THE PSYCHOSOCIAL IMPACT OF HOME USE MEDICAL DEVICES

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Abstract

Recent increases in life expectancy, combined with the rise of chronic diseases, have led to a rise in the use of medical devices to monitor and treat illnesses in people's homes. To date, however, little attention has been paid to understanding the impact that these devices have on the home environment, the users of these devices and their partners. This thesis presents three studies investigating the physical, personal and social issues faced by people using home medical devices.

The first study consisted of qualitative interviews with 12 device users and seven partners and investigated their experiences of home use medical devices. Analysed thematically, this study described how medical devices can foster or threaten people's experience of the physical, personal and social aspects of the home environment when medical devices are integrated into their homes.

In study two, a questionnaire was developed to investigate the attitudes of healthcare professionals and patients about the relative importance of different medical device characteristics. Different groups of healthcare professionals involved with the provision of medical devices were included (doctors, nurses, pharmacists) as well as medical device users and non-users. The results showed that practical factors (user testing, clear instructions, clinical trials, reducing appointments, training and cost effectiveness) are viewed as more important by professional groups than factors that relate to the home environment (choice and appearance). This indicates a lack of a whole person approach to patient care and the selection of home medical devices.

In the third study longitudinal interviews were carried out with four couples, where one of the couple had been diagnosed with Chronic Obstructive Pulmonary Disease (COPD) and prescribed an oxygen concentrator to use at home. The aim of this study was to discover how couples experience the process of being given a medical device to use at home over time. The interviews identified that being given an oxygen concentrator can be the source of an acute

episode of uncertainty for some couples and the process of coping was mediated by the expectations that they had prior to being given the device.

This research has provided a valuable insight into the poorly understood impact that medical devices have on people's experience of the home environment.

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Thomson, R., Martin, J., and Sharples, S. (2013). The psychosocial impact of home use medical devices on the lives of older people: a qualitative study. *BMC Health Services Research,* 13(1), 467.

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Chapter 1: Introduction

1.1 Background

In the United Kingdom (UK) between 1985 and 2010 the number of people over 65 increased by 17% to 1.7 million and it is predicted that by 2034, nearly a quarter of the population will be aged 65 or over (Office of National Statistics, 2012). A similar trend in increased life expectancy is being seen in Western Europe, Japan and the United States (US) (Leon, 2011). One result of an aging society and an increase in life expectancy is the rise in chronic diseases (e.g. osteoporosis, diabetes, arthritis and Chronic Obstructive Pulmonary Disease), a trend that is placing considerable strain on healthcare budgets and systems. It is estimated that the care and treatment of people with long term conditions accounts for 70 percent of the UK primary and acute care budget (Department of Health, 2012a).

Studies have shown that long-term conditions might be controlled by patients monitoring and caring for themselves (World Health Organisation, 2008; Lathan et al., 1999). As a result, the home is increasingly becoming the setting for different forms of healthcare (Arras & Dubler, 1994), a trend often described as the 'medicalisation of the home'. This, in turn, has led to an increase in the number of healthcare technologies, medical devices and assistive equipment being used in the home as part of healthcare and clinical interventions (Bitterman, 2011).

Medical devices can be used to achieve different health related outcomes (e.g. diagnosis, treatment or monitoring) but they are distinct and separate from drugs or other metabolised treatments (MHRA, 2014a). Not all medical devices that are used in the home are designed specifically for use in the home. In fact, many manufacturers do not specify whether their devices are for home-use or hospital-use (Weick-Brady & Lazerow, 2006) even though there are significant differences between the two environments. Users of medical devices in

healthcare settings are likely to be experienced, trained, professional staff while users of home medical devices are likely to be a heterogeneous group of non-professionals (family members or carers using the equipment on the patient) or patients using the device on themselves (Bitterman, 2011). Hospitals and clinics are regulated environments in which medical devices are used where, noise, illumination, sterility, heat and position of furniture are all variables that are, in general, subject to greater control than domestic environments that are unique and largely unknown to the manufacturer and issuer of the medical device (Clarkson et al., 2004; Dyck, et al., 2005).

While these views highlight differences between the medical and home environments they only consider 'home' in terms of its physical qualities. However, even in everyday parlance, it is recognised that home is more than a space filled with furniture and carpets. Ruddick (1994) touches on this issue when suggesting that healthcare converts the home environment from a place that is commonly thought of in terms of security, comfort and liberty into a place associated with discomfort, intrusion and compliance as a result of the presence of different types of hospital equipment. What is unclear and motivates the work contained in this thesis is: what is meant by the term 'home' and how does the introduction of medical devices threaten or support people's experience of home and therefore their adjustment to living with a medical device? In order to explore these issues two qualitative interview studies will be conducted with home medical device users. The results of a questionnaire will also be used to understand what healthcare practitioners consider important in relation to home medical devices and how the home environment is considered in the selection of patients' medical devices.

1.2. Contributions of this research

This research has contributed to knowledge by highlighting the impact that medical devices have on different aspects of the home environment. The findings demonstrate the ways that medical devices can influence the physical, personal and social aspects of the home environment.

This research has also found that couples who are given an oxygen concentrator to use at home can experience acute episodes of uncertainty that require the adoption of different coping strategies in order to adjust to this new situation. The ease with which these couples adjusted to life with the oxygen concentrator appeared to be mediated by the expectations that they had about the device.

In the process of conducting this research, a wealth of experience has been gained in healthcare interviewing in the home environment. This thesis presents the knowledge gained from these experiences with the purpose of providing suggestions and ideas that other researchers may learn from in terms of recruitment, safety, interviewing outside the clinical environment and the emotional challenges of conducting healthcare research in participant's homes.

1.2 Organisation of this thesis

The following section sets out the chronological phases of the research and provides a summary of thesis chapters.

1.2.1 Summary of the phases of this research

This research consisted of the following phases. First a literature review was conducted which led to the formulation of three research questions and a pragmatic research approach and methodology was formulated to address those research questions. An exploratory qualitative interview study was conducted with 12 users of home medical devices and seven of their partners. The findings of this study helped inform two subsequent studies that were conducted concurrently. The first of these was a questionnaire study distributed to healthcare professionals and user groups. The second was an in-depth, longitudinal qualitative study conducted with patients and their partners who were given an oxygen concentrator to use at home. The results of the three studies were then presented at four stakeholder events in order to validate and obtain feedback on those findings.

1.2.2 Summary of the thesis chapters

Chapter 1: Introduction

This provides an outline of the thesis including the background and motivation for the research, the structure of the thesis and its contributions to knowledge.

Chapter 2: Literature review

The literature review focuses on:

1. concepts of space and place in relation to understanding what constitutes a 'home'. It also proposes an eight point working model of different aspects that contribute to the experience home.

2. issues surrounding the medicalisation of the home, the transformative effects different technologies have on the home environment and the experience of patients who have used and interacted with medical devices in the home.

3. medical management of chronic illness and long-term conditions, in particular how patients and their partners cope and adjust to the types of medical condition that home medical devices are increasingly being used to monitor and treat.

Based on the literature review and the aim of this research (to understand how the introduction of medical devices impacts on people's experience of home), three research questions were formulated, which informed the design of the three individual studies:

- *How are medical devices integrated into the homes of users?*

- *What do different groups of healthcare professions consider important in relation to home medical devices?*

- *What is the lived experience of couples who are given a medical device to use at home and how does this change over time?*

Chapter 3: Methodology

This chapter sets out the methodological foundations for this thesis. It starts by providing an overview of different research paradigms, and a rationale for the pragmatic approach adopted in this study. It then goes on to outline the different qualitative and quantitative research strategies selected in order to answer the research questions and discuss the rationale behind the selection of interview participants.

Chapter 4: An exploratory study looking at the integration of medical devices into the home environment

Chapter four describes the results of an exploratory, qualitative interview study that investigates the integration of medical devices into the home environment. This study identifies and describes some of the challenges faced by 12 users of home medical devices and 7 of their partners in relation to medical devices used in the home. In particular, it considers the impact of medical devices on the physical, personal and social aspects of home.

Chapter 5: What do different groups of healthcare professions consider important in relation to home medical devices?

Chapter five describes the results of an on-line questionnaire that was given to different groups of healthcare practitioners and device users/non-users in order to rank nine factors or characteristics associated with home use medical devices in order of importance. Open questions were also use to help clarify the quantitative findings. The results of this study show that factors relating to the practicalities of using a device are generally considered more important that factors relating to user satisfaction, suggesting a lack of a whole person approach to patient care and a more paternalistic approach to home medical device selection.

Chapter 6: Adjusting to life with an oxygen concentrator

Chapter six presents the results of a longitudinal, qualitative interview study with couples where one person had been diagnosed with chronic obstructive pulmonary disease and had been given an oxygen concentrator to use in the home as part of their treatment. The results of this study illustrate that there is a process to go through with regards to coping and adjusting to having an oxygen concentrator in the home and that different issues have to be negotiated as the couples adjust to their changing lives.

Chapter 7: Stakeholder feedback

Chapter seven describes four stakeholder feedback events that were arranged with six healthcare professionals and one non-professional. The aims of these were to disseminate the findings of the studies; obtain feedback on those findings; use the feedback to help contextualise these findings in relation to current healthcare practice.

Chapter 8: Reflections and learning points from interviewing participants in their own homes

Chapter eight presents a personal reflection on some of the challenges encountered during the interview-based studies conducted in this research. It provides suggestions and ideas for other researchers on how they may navigate issues that may occur in similar research areas.

Chapter 9: Conclusion of thesis

This final chapter summarises the research presented in this thesis, sets out the contributions to knowledge, provides a discussion of the limitations of this research, and closes with potential avenues of research that may build upon this work.

Chapter 2: Literature Review

2.1 Introduction

This review of the literature covers the key topics associated with home use medical devices and long-term conditions and consists of four parts:

Section 2.2 describes the concepts of space and place in relation to house and home and proposes an eight point working model of different aspects of home discussed in the literature.

Section 2.3 reviews the literature surrounding the medicalisation of the home, the transformative effects different technologies have had on the home environment and the experience of patients interacting with medical devices in the home.

Section 2.4 reviews the literature concerning the medical management of chronic illness and long-term conditions and how patients and their partners cope and adjust to this type of medical condition.

Section 2.5 summarises the reviewed literature and how it relates to the work reported in this thesis.

In the search for primary research studies, reviews and theoretical articles, four electronic databases were prioritised for searching: Psycinfo, EBSCO Host, Science Direct and Google Scholar. The reference lists of relevant articles identified through the databases were also searched in order to identify other potentially useful references in a citation pearl-growing approach as described by McColl et al. (2002).

2.2 What is 'home'?

This section provides an account of the 'space' and 'place' literature and how it relates to the notions and differences between 'house' and 'home'. This is

followed by different features or qualities that homes possess and the proposal of an eight point working model of the aspects of home.

2.2.1 Space and place

There are many approaches to understanding the concept of home; however, most definitions acknowledge that home is a ‘place’ situated first and foremost in physical ‘space’. The terms space and place are considered fundamental geographic concepts with different meanings and usage (Casey, 2001).

Space, according to Malpas (2014) implies openness or 'room' and as such there is a close conceptual relationship between space and void. A space or void is a three-dimensional environment that is both quantifiable and measurable in which objects may be positioned and events occur (Harrison & Dourish, 1996). Thus, space may be the void in which the universe exists or an enclosed area, for example, a room in a building. The former measured in light years, the later in metres and centimetres.

According to Tuan (1977) space can be described as a location that holds no particular connections for a human being; it is devoid of personal value and no meaning has been ascribed to it (Tuan, 1977).

In direct contrast to the notion of ‘space’ as neutral, objective segments of physical space; ‘place’ can be described as a valued space which is imbued with personal meaning and cultural expectations (Harrison & Dourish, 1996). Tuan (2004, p4) coined the term *topophilia* to describe “the affective bond between people and place”. The reason for this bond is that people make places from spaces. This can be achieved at an individual, group or national level. While a teenager may put up a poster of their favourite band on their bedroom wall, neighbourhoods or councils may plant flowers in communal parks and countries may use state buildings, sporting events and tourism as ways to express them to the rest of the world. What is common to each of these examples is that people are responsible for transforming a neutral physical space into a meaningful location (Cresswell, 2004).

Agnew (1987) outlined 'location', 'locale' and 'sense of place' as fundamental aspects of a meaningful place. The first aspect, location, refers to the fact that all places have a location; they have co-ordinates that allow them to be found on a map (this includes locations that may change over time for example ships or trains). Locale in this instance means the material or physical place for social relations to take place. Whether that is a city (which is collection of buildings, roads, gardens etc.) or a bedroom (which may consist of a door, a window, a bed or wardrobe) places are material things. Finally, 'sense of place' refers to the qualitative, subjective and emotional attachment people have to a place, whether in the present (where we now live) or in the past (where we have lived).

While the terms space and place are related, what is widely agreed is that place is not space. Space is something abstract, without any substantial meaning while place can be seen as space that has been given meaning. In a particularly effective example, Harrison and Dourish (1996) illustrate this difference using a smokers' corner outside a work place as an example. While this would be considered a not very appealing physical space to the non-smoking employees, to the smokers who congregate there, not only to smoke, but maybe also to socialise with colleagues, this space is a place – a space with value and meanings. The process of investing space with meaning has happened throughout history and across cultures (Cresswell, 2004):

> *What begins as undifferentiated space becomes place as we get to know it better and endow it with value . . . The ideas ''space'' and ''place'' require each other for definition. From the security and stability of place we are aware of the openness, freedom and threat of space, and vice versa. Furthermore, if we think of space as that which allows movement, then place is pause; each pause in movement makes it possible for location to be transformed into place. (Tuan, 1977: 6)*

2.2.2 House and home

The distinction between space and place described above provides a useful theoretical framework for addressing human-environmental questions regarding house and home (Karjalainen, 1993).

Home is understood to be situated in space. However, it is not the physical structure of the house that is understood to make a home. A house can generally be characterised as a clearly defined and bounded physical space providing shelter, protection and concealment for its residents to satisfy basic biological needs and that may consist of separate public and private areas (Lawrence, 1987; Rapoport, 1995). It is when such spaces become imprinted with meaning that they also become homes. Hence, in the same way that houses are 'spaces', devoid of special properties and easily quantified, homes are 'places' that hold significant social, psychological and emotive meaning for the individuals that dwell there (Easthope, 2010). This difference can be understood in our everyday language through phrases such as 'living space' and 'kitchen space' to describe functional aspects of a house and terms such as 'no place like home' or 'home is where the heart is' that illustrate the emotionality of home.

That is not to say that the language we use is always clear, for example, the use of a phrase such as 'home ownership' implies that house and home are synonymous terms. Although the meaning in this case is generally well understood, other usages can be more ambiguous. For instance saying "I don't have a home" could mean the lack of access to a place to live or dwell or that the dwelling does not carry the meaning and experience of home. Although a house is an object and a part of the environment, home is best conceived of as a kind of relationship between people and their environment. It is an emotionally based and meaningful relationship between dwellers and their dwelling places (Dovey, 1985).

Homes need not be associated with houses; a tent or cave may be a beloved home for the person or family living in it. Similarly, houses do not always become

homes, even if that is what was intended. There is no guarantee of feeling at home in the place that you dwell (Karjalainen, 1993). Thus home is the result of a transformation from one state to another. Bordessa (1989 p34) suggests that there is a process of 'home making' in that "houses become homes only by some process that culminates in the locking together of self and artefact". This draws attention to the temporal, behavioural and psychosocial activity important in facilitating home making (Rapoport, 1995).

According to Dupuis and Thorns (1996), home can also provide the experience of ontological security. Ontological security is seen as a sense of continuity and order in relation to an individual's life events and experiences and is present when the following four conditions are met:,

1) The home is a constant place within the material and social environment
2) The home is a space in which the daily routines of life are performed
3) The home is a place where a person has the most control over their life due to being free from the scrutiny of the modern-day world
4) The home is a safe foundation from which identities can be constructed.

In this way home is not only defined through its physical and social space, it is the psychological experience of that space that is instrumental to how a place is likely to be considered a home.

Time also plays an important role in the transformation of a house into a home, especially in relation to family. Home is the site of family rituals and relationships that span different generations as it is also a repository of shared memories and nostalgia and the meaning of the home may change as family patterns alter (Dupuis & Thorns, 1996). In this way, the familiarity of home is simultaneously constructed as a place for one's family (Somerville, 1997).

It is important at this point to be wary of particularly rigid definitions of 'home'. As 'home' is a term endowed with personal meanings, it is fair to say that different people are likely to understand 'home' to mean different things at different times and in different contexts. For this reason, the construction or

understanding of home should be thought of as a continuous process as opposed to the result of isolated actions (Lawrence, 1987). While this makes detailing a definition of home that is relevant in all situations somewhat difficult, the literature is clear that home is first and foremost a special kind of place that has the greatest personal significance and is "the central reference point of human existence" (Relph, 1976, p.20).

While a fixed definition of home has proved problematic, the following authors have suggested different features or qualities that homes possess and that influence a person's experience of home.

Despres (1991) reviewed the literature from different disciplines concerned with person-environment relationships and identified ten qualities that influence the meaning of home (see Table 2.1). It was suggested that the ten qualities highlighted, when all present, impact on an individual's sense of home. These qualities illustrate that home is the fundamental basis of a diverse and significant range of activities that will change over time and are influenced by other events in a person's life.

Categories of ascribed meaning of home	**Definition**
Security and control	An individual's sense of feeling in control of the area and physically secure
A reflection of one's ideas and values	How individuals see themselves and want to be seen by others
Acting upon and modifying one's dwelling	That the home provides a sense of achievement and a place for self-expression
Permanence and continuity	This links the concept of home with time in which home may be a place of memories or one which has become familiar over a period

Relationships with family and friends	A place to strengthen and secure the relationship with significant others, to raise children and entertain friends and relatives
Centre of activities.	Activities may be related to simple physiological needs such as eating or support of other activities as work or sport
A refuge from the outside world	This relates to the need for privacy and "get away" from external pressures
An indicator of personal status.	Ranked among the least important categories it is relatively important for some people that their home reflects their socio-economic status
Material structure	This relates to the physical and aesthetic attributes of the actual dwelling including its surroundings and neighbourhood
A place to own	Ownership is imbued with ideas of freedom, permanency, pride and significant economic investment

Table 2.1 Ten general categories of ascribed meaning of home (Adapted from Despres, 1991)

Analysis of results from a multiple sorting task and systematic interviews led Sixsmith (1986) to propose a tripartite model of home encompassing three experiential modes; the 'physical home', the 'social home' and the 'personal home' (see Table 2.2). In this model the notion of the physical home is concerned with the physical structure, architectural style, the human space available and the extent of services and amenities available. The social home is the concept of home as a shared place and emotional environment, where relationships are conducted; it is a place to feel love and acceptance. These ideas are found in the experiences within the home of: type and quality of relationships, friends and entertainment, and the emotional environment described in Table 2.2. The personal home reflects the concept of home as the centre of meaning in terms of being the central emotional and at times physical,

reference point in life. The personal home encompasses feelings of happiness, responsibility, belonging, critical experiences, self-expression, privacy, permanence, meaningful places, time perspective, knowledge and preference to consistently return to the same place as noted in Table 2.2.

The physical home	
Categories	*Examples*
Physical structures	The enduring physical characteristics
Extent of services	lighting, heating, household equipment, garden etc. (sometimes seen as a necessary part of home)
Architectural style	some homes were meaningful because of their architectural style
Work environment	working at home is sometimes a defining aspect of home
Spatiality	spatial properties, the activities that those spaces allow and their location within the home
The social home	
Categories	*Examples*
Type of relationship	The type of relationship and personal choice over being with particular people
Quality of relationships	The quality of relationships
Friends and entertainment	People visiting the home who provide social entertainment in the home
Emotional environment	A place where there is love can often signify a home
The personal home	
Categories	*Examples*
Happiness	The experience of happy events and general feelings of happiness
Belonging	Feelings of comfort, relaxation and familiarity

Responsibility	Stability arising from ownership an responsibility
Self-expression	Behaviour in and manipulation of the place
Critical experiences	formative experiences and lived through hardships generate deep associations with home
Permanence	The continuity of home
Privacy	Interpersonal control by having the level of privacy desired
Time perspective	places exist as home whether in the past, present or future
Meaningful place	specific events taking place there
Knowledge	tied to familiarity, this aspect of home emphasises physical and social knowledge
Preference to return	i.e. in terms of a locus in space

Table 2.2 Sixsmith's categories of interdependent meanings attached to the concept of home (Adapted from Sixsmith, 1986)

Smith (1994) used the results of five sub-studies, which involved differing samples and procedures, to identify a number of attributes that contributed to a sense of home, as well as attributes that led environments to not be considered as homes (see Table 2.3). The participants in these studies responded to a series of questions concerning their current home, other homes, non-homes and the process of making a home. This identified a number of attributes that contributed to the sense of home (e.g. personal freedom and privacy). The 'non-home' attributes identified were the mirror image of the 'sense of home' attributes and as such served to affirm each form of its expression. For example, the identification of 'personal freedom and privacy' confirms the important contribution of the reverse of this to the experience of home, that is, a 'lack of personal privacy and freedom'.

A. Contributors to a sense of home
1.Suitable physical environment
2. Positive social relationships
3. Positive atmosphere engendering feelings of warmth, care and cosiness
4. Personal privacy and freedom
5. Opportunities for self-expression and development
6. Sense of security
7. Sense of continuity
B. Contributors to environments not considered to be homes
1. Lack of personal freedom and privacy
2. Dissatisfaction with the internal social relationships
3. Poor physical environment
4. Negative atmosphere within the home
5. Lack of personalisation
6. Lack of permanence
7. Lack of security
8. Lack of ownership

Table 2.3 Smith's (1994) essential contributors to (A) a sense of home and, (B) environments not homes (Adapted from Smith, 1994).

Annison (2000) notes that based on the literature detailed above, the concept of home is revealed to be multi-faceted and features many contributory qualities. Although no single feature alone enables the realisation of a true home, the absence of any one of these features may transform what was previously a home into a non-home for the individual or family living there.

Somerville (1997) identified remarkably similar categories across the sociological and non-sociological literature and highlighted the need to bring together findings from different disciplines to agree an integrated theory of what constitutes home. He states that "every aspect of the meaning of home can be internally explicated as a physical/psychological/social construct and related to the wider complex of which it is an integral part" (Somerville, 1997, p. 226). By synthesising the concepts proposed by Despres (1991) from the architecture and

housing literature and those identified by Smith (1994) and Sixsmith (1986) from the arena of environmental psychology, a list of factors (see table 2.4) is proposed as a working model.

Aspect of home	Experiential modes	Reference
The physical environment	*Physical home*	Despres (1991), Sixsmith (1986), Smith (1994)
Provides privacy	*Personal home*	Despres (1991), Sixsmith (1986), Smith (1994)
Offers security and safety	*Personal home*	Despres (1991), Smith (1994)
Promotes a sense of control	*Personal home*	Despres (1991), Sixsmith (1986)
Allows opportunities for self-expression	*Personal home*	Despres (1991), Sixsmith (1986), Smith (1994)
A place to foster relationships	*Social home*	Despres (1991), Sixsmith (1986), Smith (1994)
A place to go from/return to	*Personal home*	Despres (1991), Sixsmith (1986)
Provides a sense of permanence/continuity	*Personal home*	Despres (1991), Sixsmith (1986), Smith (1984)

Table 2.4 Proposed working model of aspects of home

It is acknowledged that this model is not, and never realistically could be, exhaustive nor perfect given the multi-faceted and temporal nature of what 'home' means. However, acknowledging these limitations, the proposed model will be used throughout this thesis when discussing the results of each study.

It is worth highlighting that the everyday lived experience of home is not always the highly positive one alluded to in the literature above. While aspects of the home may provide sanctuary, privacy, security and other aspects of an 'ideal'

home environment, for many ‘home’ is associated with a negative emotional attachment. For some older people or those living with a disability or impairment, home can become either a virtual prison leading some to stay-at-home, rarely able or willing to venture beyond the front door. Furthermore the poor physical design of a dwelling can make aspects of daily living a tremendous burden (Imrie, 2007; Sixsmith & Sixsmith, 2008). Similarly, some feminist writers have argued against the romanticised images of the home by suggesting that the home can be better thought of as a place of captivity and isolation for some women (Allan, 1985; McDowell, 1983). It is, as Goldsack (1999, p. 121) notes, “less of a castle, and more of a cage”. In this way, home can be thought of in terms of the drudgery of domestic work more than a place for personal pleasure. Likewise, research with women who experience domestic violence has demonstrated that as much of the violence takes place within the home, the myth of home as a place of safety is replaced by one where home is experienced as a place of fear and painful memories (Kuribayashi & Tharp, 1998).

2.2.3 Summary and implications for this research

This section has discussed the idea of home in relation to space and place. It has illustrated that home can be regarded as a special type of place. While space can be thought of a three-dimensional, quantifiable environment, place is imbued with personal meaning and is qualitative in nature. In the same way, although a house is an object and a part of the environment, home is best conceived of as a kind of relationship between people and their environment. Home is an emotionally based and meaningful relationship between dwellers and their dwelling places. While there is little support for a rigid definition of home, some authors have proposed different aspects or qualities that homes may possess and may influence people’s experience of home. The proposal of a working model of different aspects of home, synthesised from the literature, provides a useful tool by which to discuss any transformative effects medical devices may have on the home environment.

2.3 The medicalisation of the home

This section will describe the increasing migration of healthcare into the home environment and the transformative effect this may have on the home environment. It will then set out what is meant by the terms medical device and home use medical device and discuss four studies (Ingadottir & Jonsdottir, 2006; Lehoux, 2004; Fex et al., 2009 & , Avril-Sephula et al., 2014) that have looked at medical device use in the home and users' interactions with those devices.

2.3.1 Healthcare in the home environment

The home is increasingly becoming the setting for different forms of healthcare and new healthcare technologies, medical devices and assistive equipment are expanding the number of healthcare and clinical interventions that can be employed in the home (Bitterman, 2011). This trend – often termed the 'medicalisation of the home' - has been of interest to researchers in the social sciences (e.g. psychology and, sociology). It has been suggested that clinical interventions in the home may have a transformative effect on the inherent characteristics of the home and create ambiguities between 'home' and 'institution' which may erase or reverse any positive notions that people may have for the home (Martin, et al., 2005; Percival, 2002).

Dyck et al., through analysis of interviews and field observation with adults receiving care in the home, identified processes through which the home is reconstructed as caregiving space. Care services directed to one participant resulted in a blurring of the boundaries between private and social space in the home. For example, the bedroom became an ambiguous space, both private and public, as not only was it a place to sleep at night it was also the site where care services attended to her personal hygiene needs at an intimate level.

An important and often overlooked facet of the medicalisation of the home is that patients often have partners and family members living with them, all of whom may have an attachment to the home. For example, a seriously sick person's presence in the home may place new, sometimes complicated,

demands upon the other members of the household, for example, the need for medical technology to be monitored or maintained. This may result in days having to be rescheduled and rituals to be abandoned, such as eating at a certain time and place. It may also result in rooms within the house taking on different functions resulting in other household members' loss of privacy or freedom, which can create stress between family members (Arras & Dubler, 1994; Conradson, 2003; Teeland, 1998).

2.3.2 The transformative effect of technology on the home

Most of the literature on how technology has transformed homes has focused on those devices that designed for the provision of comfort, sanitation, entertainment or intended to be labour saving (Lewi & Smith, 2007).

Cowan (1976 p1) describes this as "the industrialization of the home" and describes the transformative effect this has had on our daily lives. She describes how for American women in the 1920s the introduction of technologies such as: electric irons, electric washing machines, electric lights, indoor plumbing and centrally heated water, led to new domestic jobs being created, rather than making life easier for them and freeing up their time. While these jobs were not as physically demanding, they often took up as much time as the jobs they had replaced. For this particular group, therefore, the home may be considered less of a place of dwelling, but more likened to an industrial workplace.

Televisions have also had a transformative effect on our home lives. The arrival of television into the home, now regarded as commonplace, was initially problematic as it involved the moving around of furniture and the reorganising of family routines and practices. The television set has now superseded the hearth as the centre piece of the family living area and in doing expresses something of the owners' or family's tastes or identities (Morley, 2007). A similar process of acceptance and integration into the home has been noted with other technologies such as the telephone, radio and computer. Berker et al, (2005 p2) have described this process as "domestication" as it can be seen as a situation

when users are confronted with new ('strange' and 'wild') technologies that need to be 'house-trained', i.e. integrated into environmental structures and household routines. This implies that, at a symbolic level, technologies, like pets, can become part of the family. Domestication may be deemed successful when a new technology ceases to be problematic, challenging or the focus of family conflict but becomes comfortable, useful and reliable (Berker et al. 2005; Haddon, 2006).

2.3.3 Healthcare related home modification

The practice of occupational therapy has recently begun to emphasise the importance of understanding the role of the environment in home modification (Aplin et al., 2013). Heywood (2005) holds the view that housing adaptation for a disabled or chronically ill person should be a transformation in which the barriers that have turned someone's dwelling into a place of burden and confinement are removed and their home is restored to them. Three qualitative studies have focused on the transformative effect home adaptations (due to ill-health or disability) have had on recipients. Drawing on a conceptual framework based on the work of Sixsmith (1986) and Smith (1994), both Tanner, et al. (2008) and Aplin et al. (2013) analysed interviews of people who had received home adaptations in relation to the 3 modes of experience: 'the physical home', 'the personal home' and 'the social home'. Haywood (2005) used a working model of 9 aspects of the meaning of home influenced by the literature but also the data collected from which to discuss her findings. The types of home adaptation in these studies included both major modifications such as: installing through-floor lifts (lifts in the home that go from a downstairs room in to the room above), widening doors and modifying bathrooms, through to minor modifications that included the installation of ramps and handrails. While all three studies demonstrated the restorative effect home adaptations can have on the meaning and experience of home for people with illness or disability, they also highlighted instances where adaptations actually threatened aspects of home and had a negative effect on people's experience of home. Most notably, all three studies

provided instances where the aspect of home concerned with a 'sense of control' had been threatened. This happened when an occupational therapist's emphasis on alleviating a patient's functional limitations seemed to take precedence over a more holistic view of needs and a collaborative decision making process.

Some modifications also threatened the home as a reflection of self. Both Aplin et al. (2013) and Haywood (2005) highlighted instances where patients were concerned that the modifications acted as a constant reminder of their illnesses or disabilities or made their houses resemble a hospital. Haywood also described how relationships were threatened by adaptations as they often reduced the area of usable space for other family members. This lost space meant more overcrowding, and led to strain on relationships. Based on these findings, Haywood proposed a more collaborative approach to the provision of home modifications that promotes understanding and values client's experience of home in order to achieve a more holistic approach to practice.

A literature review by Wielandt and Strong (2000) considered the factors that were associated with compliance with prescribed adaptive equipment. Equipment that was rated highly for attractiveness by users was associated with better compliance than equipment rated as unattractive. They also found that low compliance was associated with devices that were poorly suited to the use environment. As a result, it has been recommended that the client's home environment be assessed not just in terms of whether the device is suitable for the physical surrounding (e.g. not too big) but also in terms of the other people that live in the home (Hoffmann & Mckenna, 2004). To help maximise the fit between user, equipment and environment, it has been suggested that users should be increasingly involved in the selection of the device while considering how it will fit and be incorporated in to the user's lives (Gitlin et al., 1996).

2.3.4 What are medical devices?

There are various definitions of what constitutes a medical device. The most commonly used definitions are found in regulatory documents and thus have a

legal function which is reflected in the legal terminology and precise language. The three most commonly referred to definitions are presented in Figure 2.4.

All of these definitions share the view that a medical device can be used to achieve different health related outcomes (e.g. diagnosis, treatment or monitoring) but that they are distinct and separate from drugs or other metabolised treatments.

	International Organization for Standardization 13485:2003	USA Federal Food Drug & Cosmetic Act (2011)	European Council Directive 2007/47/EC
General	Any instrument, apparatus, implement, machine, appliance, implant, in vitro reagent or calibrator, software, material or other similar or related article, intended by the manufacturer to be used, alone or in combination, for human beings for one or more of the specific purpose(s) of:	An instrument, apparatus, implement, machine, contrivance, implant, in vitro reagent, or other similar or related article, including a component part, or accessory which is:	Any instrument, apparatus, appliance, software, material or other article, whether used alone or in combination, together with any accessories, including the software intended by its manufacturer to be used specifically for diagnostic and/or therapeutic purposes and necessary for its proper application, intended by the manufacturer to be used for human beings for the purpose of:
Specifics	• diagnosis, prevention, monitoring, treatment or alleviation of disease, • diagnosis, monitoring, treatment, alleviation of or compensation for an injury, • investigation, replacement, modification, or support of the anatomy or of a physiological process, • supporting or sustaining life, • control of conception, • disinfection of medical devices, • providing information for medical purposes by means of in vitro examination of specimens derived from the human body	• recognized in the official National Formulary, or the United States Pharmacopoeia, or any supplement to them, • intended for use in the diagnosis of disease or other conditions, or in the cure, mitigation, treatment, or prevention of disease, in man or other animals, or • intended to affect the structure or any function of the body of man or other animals	• diagnosis, prevention, monitoring, treatment or alleviation of disease, • diagnosis, monitoring, treatment, alleviation of or compensation for an injury or handicap, • investigation, replacement or modification of the anatomy or of a physiological process, • control of conception
Caveat	and which does not achieve its primary intended action in or on the human body by pharmacological, immunological or metabolic means, but which may be assisted in its function by such means.	and which does not achieve its primary intended purposes through chemical action within or on the body of man or other animals and which is not dependent upon being metabolized for the achievement of any of its primary intended purposes.	and which does not achieve its principal intended action in or on the human body by pharmacological, immunological or metabolic means, but which may be assisted in its function by such means

Figure 2.1 Official definitions of medical devices

There is some overlap between medical devices and assistive devices. Assistive devices (often referred to as assistive technology or 'aids for daily living') are intended for the alleviation or compensation for a disability and as such may be considered a medical device and subject to the same legislation. Assistive devices may be classed as a medical device if there is a stated medical purpose and if there is a direct link between the corrective function of the equipment and the individual concerned. For example, hearing aids, walking sticks and hoists may be considered medical devices, while grab rails, ramps and commodes would be considered aids for daily living (Medicines and Healthcare Products Regulatory Agency (MHRA), 2014a). The work described in this thesis includes some devices which cross over the boundaries between medical and assistive device, such as stairlifts, but only when there was a stated medical need for that particular device.

2.3.5 What are home use medical devices?

There are a number of different medical devices that are used in the home environment, for example, oxygen concentrators and peritoneal dialysis equipment. There is, however, no clear internationally recognised definition for such devices (Gupta, 2007). This position is further confounded by the fact that not all medical devices that are used in the home are designed specifically for use in the home. In fact, many manufacturers do not specify whether their devices are for home-use or hospital-use (Weick-Brady & Lazerow, 2006).

In the US some progress has been made with regards to understanding and defining exactly what a home use medical device is. In 2014 the FDA issued a guidance document for Industry and FDA staff titled 'Design Considerations for Devices Intended for Home Use' (FDA, 2014). In this document a definition of a home use medical device is given as:

> *"A medical device labeled for use in any environment outside a professional healthcare facility. This includes but is not limited to outdoor environments, office*

environments, schools, vehicles, emergency shelters, and independent living retirement homes. If the device is intended to be used in professional healthcare facilities and also outside those facilities, it meets this definition" (p3).

A professional healthcare environment is defined as one in which personnel with medical training are continually available to oversee or administer the use of medical devices. This document also differentiates between lay users (a patient, caregiver, or family member that directly uses the device or provides assistance in using the device) and qualified healthcare professionals (licensed or non-licensed healthcare professional with proficient skill and experience of the device that they can aid or train patients and caregivers to use and maintain the device) (FDA, 2014b).

This definition highlights the two aspects of home use medical devices: users (i.e. lay people or non-professional people), and environments (non-clinical or transitory environments), that are major differentiating factors of home use medical devices.

2.3.6 The experience of using medical devices in the home

Ingadottir and Jonsdottir (2006) conducted interviews with six users of home ventilators and five of their spouses. Interpretive phenomenology and narrative analysis were used to analyse the data and helped to reveal what it is like to be a person dependent on technological treatments. Participants seemed split as to whether the experience of using the technology was seen as a complete life saver or considered meaningless exertion. They found that usage of the home ventilator not only required constant commitment and time but also put limitations on activities of daily living and recreational pursuits. Users found their ability to travel diminished, which led to feelings of isolation. The treatment also required time to maintain and clean masks, headgear and tubes and to change the filters. Physical limitations were also noted due to ventilators taking up space in the home. Some oxygen compressors needed to be placed outside the

bedroom during night because of the noise it generated and led to one spouse occasionally sleeping in a separate bedroom to regain lost sleep due to the noise from the machine and the mask.

The patients' ventilation treatments in this study was initiated based on the health professionals' judgments with little regard to patients' and families' preferences, trusting that that was in their best interest. Users of these devices experienced being confronted with a treatment that they struggled to fit into their lives.

Ingadottir and Jonsdottir (2006) note that in the interviews with participants the conversations mainly revolved around the experience of the patient only, and the experience of participants as a couple was not particularly well explored, which may mirror the limited emphasis that seems to be placed on families as a whole in today's healthcare (Lindahl & Lindblad, 2011).

Lehoux (2004) conducted interviews and observations to understand what makes different forms of healthcare technology user-friendly and how this influences integration in to patients' private and social lives. Four common home use medical devices that vary in their technical and clinical features were studied: Antibiotic intravenous therapy (IV), parenteral nutrition (PN), peritoneal dialysis (PD) and oxygen therapy (O_2). This study discussed the technical and human factors that affect how patients use healthcare technology both at home and in their broader social lives. Although each of the home care technologies in this study provided patients with relative autonomy from the hospital and contributed to health improvements it imposed significant constraints on patients and carers.

Inside the home, technologies became a source of anxiety triggered by the possibility of potential infections and dislodging of catheters (IV & PN) and the risk of fire when cooking over a gas stove (O_2). Technologies did not always fit neatly in the home environment, for example, oxygen concentrators making rooms hot and some participants reported that they had had to make adaptions such as adding an extra set of tubing so they could use a second floor or sit

outside on a patio. One PD patient reported that they were planning to have an evacuation system installed so he would not have to dispose of the solution exiting the tubing from his peritoneal cavity through the toilet.

This study also found that devices had effects that went outside the home: O_2 patients were less likely to go out as they did not like to be seen with nasal tubes, while carers of PN, PV, and IV patients sometimes curtailed their social activities because they felt that they were needed to be on hand to assist with the treatments. The non-retired patients experienced major difficulties in continuing with employment because of the frequency and/or duration of being attached to the medical device.

Lehoux (2004) concludes that home care involves more than simply transferring a particular technology from the hospital to the home – it requires making sure that the home and social environments enable a safe, effective, appropriate and personally satisfying use of technology. The complexity of the study design e.g. the use of four different technologies and the mix of participants from different socio-economic status, gender and age meant that the interaction of these variables could not be explored, however, it does provide a broader perspective on the research problem. In addition, the carers that participated in the study were not necessarily related to a patient participating in the study and were spouses or family members (often mother or daughter) of a different person receiving high-tech home care. Thus the chance to study the effects of these technologies on people living in the same home environment was missed.

Fex et al. (2009) conducted a qualitative interview study of ten people who performed self-care at home, using either long-term oxygen therapy from a ventilator or oxygen cylinder, or who performed peritoneal or haemodialysis. Participants found managing a life so closely intertwined with technology required a learning period of accepting and mastering the technology in order to enable them to manage life at home. This study also found that the medical technology had an influence on the home environment: home dialysis and oxygen therapy equipment were generally experienced as bulky and conspicuous

and had a detrimental effect on the aesthetics of the home environment. Efforts were made to conceal this equipment in a bid to reduce the institutionalised look of the home, which suggests that medical technology needs to be adjusted both aesthetically and practically for use in the home. Limitations of this study were that just one person using a ventilator was able to participate and there was a mix of patients who had support at home making it difficult to ascertain whether this lessened or accentuated the findings.

The emotional impact of home treatments that include medical devices has also been the focus of research. Avril-Sephula et al. (2014) interviewed eight partners of people on haemodialysis and asked their views on the challenges of living with a partner on haemodialysis. Thematic analysis highlighted the emotional challenges faced by the partners and how haemodialysis forced changes in their social and relational life. The therapy was viewed as intrusive and dominating, curtailing social events and holidays. In addition, responsibilities for household tasks had changed with some partners labelling themselves as a 'carer'. That some partners saw themselves as 'carers' may in part be due to a lack of diversity in the sample as only one male partner participated.

2.3.7 Summary and implications for this research

What is clear from the literature that has looked at the use of medical devices in the home is that there is a sense that medical devices intrude into the home environment and do not fit in. The result of this is that users are required to make adjustments to the way that they live in their own homes.

The occupational therapy research around healthcare related home modifications has specifically looked at how modifications or assistive equipment impacts on different characteristics, or aspects of home. In contrast, the four studies looking at users' interaction with medical devices (Ingadottir & Jonsdottir, 2006; Lehoux, 2004; Fex et al., 2009 and Avril-Sephula et al., 2014) detailed user experience and the impact on the home was discussed mainly in relation to the physical characteristics of the environment.

This research aims to extend the work undertaken with regards to patient experiences of using home use medical devices by exploring how these devices may impact on the different aspects of home proposed by the literature.

Another area that has not been previously considered is whether the issues raised in the literature are stable or change over time. The four studies described previously have been cross-sectional in design where the views of a cross-section of people (who may have similar medical conditions or use similar devices) were collected at a single point in time to provide a 'snap shot' of common themes or issues (Spencer et al., 2013). A major focus of this research will be to adopt a longitudinal methodology in attempt to explore how the impact of using medical devices in the home changes over time.

2.4 Chronic illness and long-term conditions

This section will start by defining chronic illness. It will then describe current practice with regards to the medical management of these conditions and review the impact that long-term conditions have on both patients and their partners.

2.4.1 What are chronic illnesses and long-term conditions?

The terms chronic disease, chronic condition, life-long disease/condition, long-term disease/condition and non-communicable disease/condition are commonly used interchangeably (DoH, 2004) and this thesis will continue to observe this convention.

According to the World Health Organisation (WHO), chronic diseases are conditions for which there is currently no cure, and which are managed over a period of years or decades with drugs and other treatments. This includes a wide range of health problems that go beyond the conventional definition of chronic illness, such as heart disease, diabetes and asthma to include communicable diseases, (such as the human immunodeficiency virus), certain mental disorders (such as depression and schizophrenia) and cancers as well as disabilities and

impairments not defined as diseases, such as blindness and musculoskeletal disorders (WHO, 2003).

It is estimated that around 15 million people in England have a long-term condition (this rises to 20 million if musculoskeletal conditions are included) (DoH, 2012a). With the increasing prevalence of long-term conditions (see table 2.5), in particular people having two or more conditions, limiting long-term conditions continue to require a disproportionate share of health and social care services, including community services, urgent and emergency care and acute services (Office for National Statistics, 2009):

- 50% of all GP appointments
- 64% of outpatient appointments
- 70% of all inpatient bed days
- In total around 70% of the total health and care spend in England (£7 out of every £10) is attributed to caring for people with LTCs
- This means that 30% of the population account for 70% of the spend

Type of Long-Term Condition	Numbers affected		% Change
	2006/07	2010/11	
Hypertension	6,706,000	7,460,000	11%
Depression	0*	4,878,000	N/A
Asthma	3,100,000	3,273,000	6%
Diabetes	1,962,000	2,456,000	25%
Coronary heart Disease	1,899,000	1,878,000	-1%
Chronic Kidney Disease	1,279,000	1,855,000	45%
Hypothyroidism	1,367,000	1,667,000	22%
Stroke or Transient Ischaemic Attacks	863,000	944,000	9%
Chronic Obstructive Pulmonary Disease	766,000	899,000	17%
Cancer	489,000	876,000	79%
Atrial Fibrillation	692,000	791,000	14%
Mental Health	380,000	438,000	15%
Heart Failure	420,000	393,000	-6%
Epilepsy	321,000	337,000	5%
Dementia	213,000	267,000	25%

Table 2.5 Prevalence of Long term conditions on Quality and Outcomes Framework disease registers (source: DoH, 2012a)

2.4.2 Medical management of long-term conditions

As chronic diseases, by definition cannot be fully cured, the goal of chronic illness care is to manage symptoms and reduce disability (Larsen & Hummel, 2013). Until recently, there was no differentiation between the ways chronic conditions were managed as opposed to acute diseases: the healthcare process being initiated when the patient visits their doctor with symptoms of ill health and the doctor reacts by instigating diagnostic interventions and medical treatments aimed at reducing or solving the health concerns. This 'problem-solving' orientated model paid little attention to either proactive or preventative management or the involvement of other healthcare disciplines and the role of the patient was seen as being confined to passively complying with the prescribed therapy (Rijken et al., 2014).

In a bid to move away from this biomedical view surrounding the management of long-term conditions, perhaps the most widely adopted approach to guide chronic care improvement is the Chronic Care Model (CCM) (Wagner et al., 1996; Wagner et al., 2001). The chronic care model (CCM) is a framework for managing chronic illness, which facilitates planning and coordination among providers while helping patients to play an active informed role in managing their own care. The model contains six major elements that interact to produce high-quality, evidence-based care and interventions at individual, community and healthcare organisational levels (Wagner et al., 2001) (see table 2.6).

CCM Element	Goal
1. Self-Management Support	Empower and prepare patients to manage their health and healthcare.
2. Decision Support	Promote clinical care that is consistent with scientific evidence and patient preferences
3. Delivery System Design	Assure the delivery of effective, efficient clinical care and self-management support.
4. Clinical information systems	Organize patient and population data to facilitate efficient and effective care.
5. Healthcare organization	Create a culture, organization and mechanisms that promote safe, high quality care.
6. Community Resources	Help patients access needed services in the community.

Table 2.6 Chronic Care Model Elements and Goals adapted from Wagner et al. (2001)

In recognition that the values and structures of the NHS, particularly in primary and community care, are somewhat unique to the United Kingdom, the NHS and Social Care Long Term Conditions Model was proposed (see figure 2.2). This model draws heavily on the CCM but also stratifies patients with long term conditions into three distinct groups based on their degree of need: level 1, level 2 and level 3 with the aim of improving the health and quality of life of those with long term conditions. (DoH, 2005).

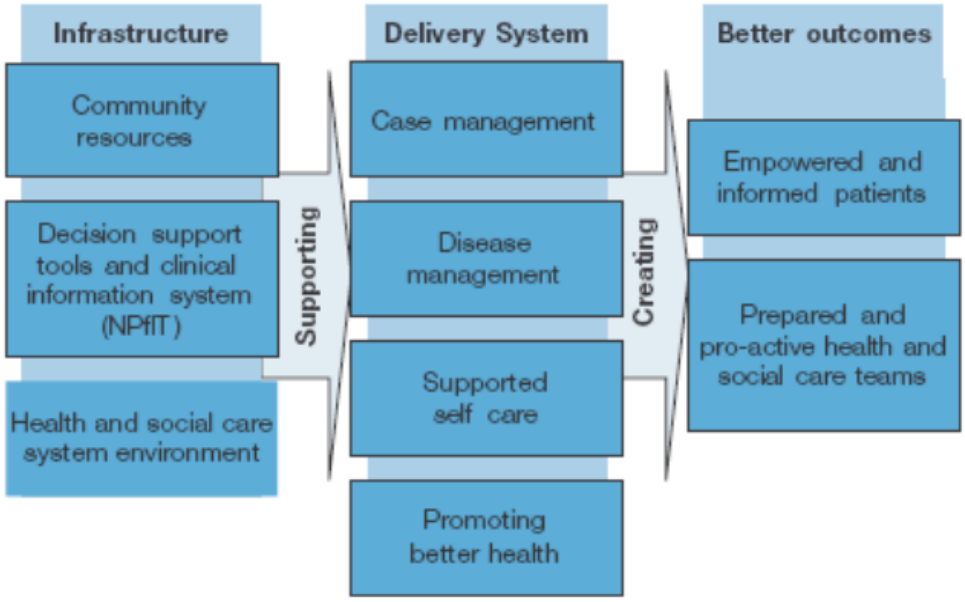

Figure 2.2 NHS and Social Care Long Term Conditions Model (DoH, 2005)

This model outlines how people with long-term conditions will be identified and receive care according to their needs: Level 1: Supported self-care, Level 2: Disease-specific care management and Level 3: Case management. It underlines the importance of the Expert Patients Programme which aims to provide local training for patients, acknowledging that the patient is his/her own expert in understanding their condition, which will help motivate and empower patients to manage their own health (Novak, 2013). Healthcare practitioners are encouraged to relinquish paternalistic patient management and instead involve people in their own care in order to improve the health and quality of life of those who have long-term conditions. Thus the clinician's role shifts from that of professional expert who instructs and decides to that of a guide who supports and advises (Greenhalgh, 2009). Integral to the ability of patients to monitor their own condition and administer their own therapy is the increasing availability of medical devices that can be given to patients (Mirel et al., 2011). These devices may be bought by the patients themselves or provided by doctors, nurse or other allied healthcare professionals (e.g. pharmacists, physiotherapists) either based in the hospital or community.

While the NHS and Social Care Long Term Conditions Model provides an opportunity for better collaboration, resulting in patient-centred care that adopts a more holistic view of the patient, it is not without barriers to successful implementation. For example, many patients are reluctant to take responsibility or seek out information for themselves – they are more than happy to trust their GPs and leave decisions to them (Auerbach, 2001; Henwood et al., 2003). Similarly, there can be an apparent reticence on the part of medical practitioners to take on this new role and when patients try to negotiate with healthcare professionals they can have their views and opinions rejected or dismissed (Fox et al., 2005; Tang & Anderson, 1999).

The NHS and Social Care Long Term Conditions Model also promotes a multi-disciplinary approach where teams of staff that may include doctors, nurses, pharmacists, based in hospitals and also in the community, will be encouraged to work together with people with long-term conditions and their families (Ham & Singh 2006). The delivery of healthcare by a coordinated team of professionals has always been assumed to be a good thing as patients benefit from the insights of different bodies of knowledge, and a wider range of skills. Despite this, however, a team approach to care remains a source of confusion and some scepticism, for example, which disciplines are essential on the team? And what do the team members other than the doctor do to support patient care? (Wagner, 2000).

Each healthcare profession has a different culture, which includes values, beliefs, attitudes, customs and behaviours, but it has been suggested that the drive to increase joint working between practitioners is leading to a blurring of traditional roles amongst healthcare staff which can challenge the effectiveness of inter-professional teamwork (Hall, 2005; Baxter & Brumfitt, 2008). Patient care teams that have the potential to meet the needs of people with long-term conditions are teams where members' roles are not only clearly defined but where responsibility for the care of the patient can be shared effectively between the team (Wagner, 2000).

2.4.3 The impact of long-term conditions on patients and partners

Physical health is closely related to emotional and mental health, (Felton & Revenson, 1984) and the diagnosis of a serious chronic illness marks the start of a period of significant distress and adjustment for both patients and their spouses (Berg & Upchurch, 2007).

Stanton et al. (2001) defines adjustment as the presence or absence of diagnosed psychological disorder, psychological symptoms, or negative mood and identified five related conceptualisations of adjustment to chronic disease:

1. mastery of disease related adaptive tasks,
2. preservation of functional status,
3. perceived quality of life
4. absence of psychological disorder
5. low negative affect.

Hamburg and Adams (1967) identified several adaptive tasks in adjustment to major life events that are related to long-term illness: maintaining personal worth, restoring/maintaining relations with important others and regulating distress. Taylor's (1983) cognitive adaptation theory also highlights self-esteem enhancement and preservation of a sense of mastery as essential adaptive tasks, while, quality of life in relation to physical, functional, social, sexual, and emotional domains also denotes adjustment to chronic disease (Cella, 2001; Newman et al. 1996).

The multi-faceted nature of adjustment encompasses components that cross interpersonal, cognitive, emotional, physical and behavioural domains and owing to the fluctuations in disease progression and exacerbations in symptoms, adaptation to chronic illness is also dynamic in nature.

While socioeconomic status, culture and ethnicity, gender and personality attributes all contribute to adjustment to chronic disease, most theories of psychosocial adjustment to illness converge on the point that how individuals cope with the demands of this type of illness affect subsequent adjustment (Stanton et al., 2007)

The cognitive-appraisal model of coping proposed by Lazarus and Folkman (1984) show that a person confronted with a stressful event (such as chronic ill health) firstly evaluates this stressor in terms of potential threat to their own well-being. This event can be appraised as irrelevant, benign and positive or harmful. If the situation is appraised as a threat, the individual will make a secondary appraisal to decide on the course of action or coping strategy they will employ based on their appraisal of the threat and the resources available to them. Two general types of coping have been identified. The first is labelled as approach-oriented or active coping strategies which include: defining the problem, generating alternative solutions and weighting alternative solutions. The second type of coping identified is emotion-focused or avoidance-oriented coping that includes: minimising the problem, distancing, selective attention, wishful thinking and avoidance (Lazarus & Folkman, 1984; Myers et al., 2004).

The coping strategies people employ and, how useful they are, are likely to vary as the demands of illness change, for example, an avoidant strategy may be useful at acute points of crisis (Mishel, 1997; Neville, 2003). However, research indicates that avoidance typically predicts maladjustment over time (Stanton et al., 2001). The use of avoidant coping to manage health problems was associated with continued emotional distress during the year following heart transplant (Dew et al., 1994) and passive strategies employed by sufferers of rheumatic disease predict poor adjustment over time (Covic et al. 2003). Approach or active-oriented strategies appear to be more effective in the adjustment to chronic illness with strategies such as information seeking and pain control being associated with positive adjustment in rheumatoid arthritis patients (Keefe et al. 2002, Young 1992) and relaxation coping strategies have been found to

contribute to reductions in next-day pain as well as enhancement of positive mood (Keefe et al. 1997).

Since the 1980's a substantial amount of research has been devoted to understanding the relationship between coping with chronic illnesses and psychological adaptation based on Lazarus and Folkman's Stress and Coping paradigm. While there have been some consistent findings in relation to general types of coping and their impact on psychological outcomes it is not without its critics (Coyne & Racioppo, 2000). The main concern raised in reviews of the literature regards the gap between the process-oriented stress and coping theory and methodologies that have been used to evaluate the theory. Retrospective methods that ask people to recall how they coped with a particular experience are prone to instances of error recall as coping strategies and resultant psychological outcomes such as distress are best measured close to when they occur. In addition, little attention has been paid to the effects of impairment over time and on which coping strategies have been implemented, at what time and the perceived effectiveness of those strategies (Manne, 2002). Studies that use daily diary assessments (e.g., Affleck et al. 1999) that aim to capture changes as they occur as well as longitudinal studies (e.g. Revenson & Felton, 1989), which study changes in coping and adjustment over time, go some way to start to address these concerns.

Chronic illness begins a period of significant distress and adjustment for both patients and their spouses. Traditionally research has examined how patients and spouses adjust to chronic illness from an individualistic perspective to stress and coping i.e. the coping strategies utilised by the patient and the support provided by the spouse (Walsh et al., 1999). More recently, a dyadic approach to coping with chronic illness has been proposed that builds on the social support provided by spouses and by noting how spouses may frequently share stressors (using words such as "ours" as opposed to "mine"), pool resources, and actively engage in joint coping efforts. According to this perspective, when couples face a stressful event, such as chronic illness, the resources of partners may be required to maintain or restore a state of balance in the individual, within the couples'

relationship or in relation to other social or familial relationships (Bodenmann, 2003; Revenson, 2003). Following an extensive review of the literature Berg and Upchurch (2007) proposed a developmental– contextual model of couples coping with chronic illness across the adult life span (see figure 2.3).

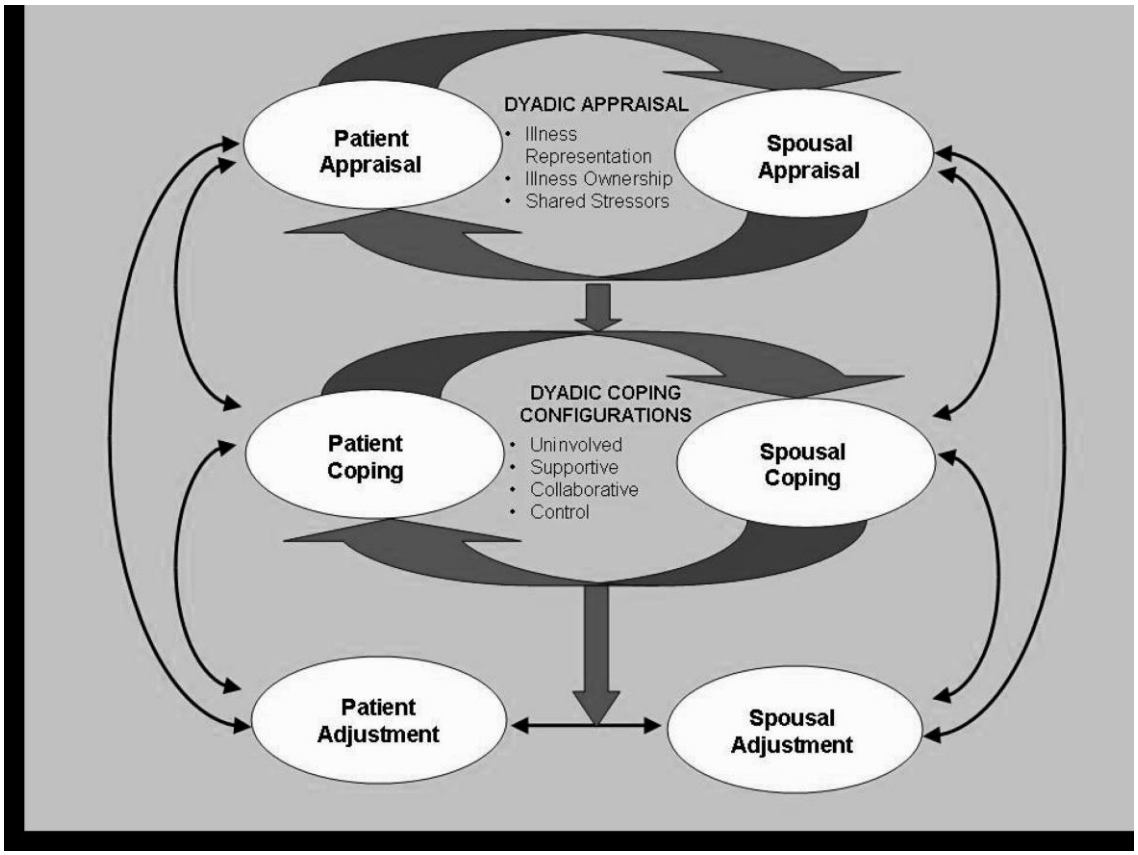

Figure 2.3 A developmental–contextual model of couples coping (Berg & Upchurch, 2007)

This approach to dyadic coping and adjustment processes emphasises that this unfolds over time and is multi-directional. The model illustrates how the patient and spouse first appraise the health threat and then adopt a coping strategy that assists them to adjust to the chronic illness. However the multi-directional aspect of this model shows that not only does patient and spouse dyadic coping affect patient and spouse adjustment, but adjustment may subsequently affect future dyadic appraisals and coping efforts. The model acts as a framework for understanding how couples coping with chronic illness may together appraise

and cope with illness not only in the long term, for example across the life span, but also in terms of the day to day aspects of illness management.

2.4.4 Summary and implications for this research

Long-term conditions are becoming increasingly prevalent and require a disproportionate share of health and social care services. There are now established models for management of long-term conditions and medical management of these conditions is moving away from a bio-medical problem solving approach to one that recognises the need for a more holistic, patient centred approach supported by multi-disciplinary healthcare teams both in hospital and the community. A consequence of this is that patients will increasingly be given medical devices to use at home. The literature recognises that the different traditions and cultures of these practitioners could affect patient care.

This research will explore whether different healthcare practitioners have different views regarding the appropriateness of the medical devices patient use in their homes.

The literature has also described the coping and adjustment processes that patients and partners undergo in relation to chronic illness, however, no research has specifically examined the effect medical devices have on these processes. This thesis will explore how users and partners cope and adjust to the medical devices that are integral to the treatment and monitoring of chronic illness over time.

2.5 Conclusion and proposed work

The purpose of this chapter has been to introduce the research topic and provide the background knowledge and research that supports it. This background knowledge has been presented as three discrete areas: ‘what is home?’, ‘the medicalisation of the home’ and ‘chronic illness and long-term conditions’. The motivation behind this is to make explicit areas where this research aims to focus

on in understanding the transformative effects medical devices have on the home environment.

We all have an everyday understanding of what we mean when we talk about house and home and that meaning is generally well understood but poorly articulated. The literature has proposed aspects or characteristics of home that while not essential in the realisation of a real home may influence people's feelings towards their home. Studies around the installation of healthcare home modifications and assistive devices have highlighted that there is an effect on the way people experience different aspects of home. The term 'home use medical device' implies a device that is compatible with the home environment. Studies that have investigated users' interactions with these devices have mainly considered the physical aspects of home, with little attention paid to the psychological and social aspects of the home environment. This gives rise to the first research question:

> *How are medical devices integrated into the homes of users?*

Medical management of chronic conditions now recognises the need for a more holistic, patient centred approach supported by multi-disciplinary healthcare teams both in hospital and the community. Home medical devices are increasingly becoming integral to the monitoring and treatment of these conditions and may be provided by different healthcare practitioners that come from different professional traditions and cultures. This literature informs the second research question:

> *What do different groups of healthcare professions consider important in relation to home medical devices?*

Coping and adjusting to chronic illness is a process that unfolds overtime, is sensitive to changes in disease progression and affects both the patient and their partner, however, the role of medical devices in this process is poorly understood. Where user interaction with home medical devices has been

studied, the cross-sectional design of those studies does not allow for the capture of any temporal aspects of adjusting to life with those devices. This informs the third research question:

> *What is the lived experience of couples who are given a medical device to use at home and how does this change over time?*

Chapter 3 will present the general methodology underpinning the data collection and analysis of this research.

Chapter 3: Methodology

3.1 Introduction

This chapter sets out the methodological foundations for this thesis. It consists of two parts.

The first section will present an overview of research paradigms and a rationale for the pragmatic approach adopted in this study will be provided.

The second section will outline the qualitative and quantitative research strategies selected in order to answer the research questions that were set out in the previous chapter.

The first part of this section will discuss the use of qualitative interviews and thematic analysis as a means to collect and analyse qualitative data. It will also discuss the rationale behind the selection of interview participants and how issues around quality in qualitative research have been addressed.

The second part of this section will describe the quantitative questionnaire approach that was selected.

3.2 Different Research Paradigms

Researchers can adopt a variety of fundamentally different strategies to generate new knowledge. Historically, research has been influenced by two major paradigms – positivism and interpretivism, which in turn determine the methods by which data are collected and analysed (Willig, 2013).

3.2.1 Positivism – a Quantitative Approach

Positivism, often regarded as the 'scientific method', proposes that reality is stable and that knowledge concerning that reality can be gathered in ways that are not subjective but are direct, objective and repeatable observations (Willig, 2008). Positivists set out to test casual explanations through the testing of theories and hypotheses, using methods that yield numbers and statistics

(Crotty, 1998). Data collected in this manner is efficient for testing pre-determined hypotheses and this approach stresses the importance of the researcher remaining objectively separate from the subject under scrutiny (Charmez, 2006).

This approach has been integral within the physical and natural sciences. However, the issue of whether the positivist paradigm is entirely suitable for the social sciences has been the focus of much debate as it has been argued such an approach fails to capture the complexity of human behaviour and social interaction (Willig, 2013).

3.2.2 Interpretivism – a Qualitative Approach

Interpretivists also believe that reality exists and can be measured, but recognise that scientists cannot avoid affecting those phenomena they study. Interpretivists propose that there can be multiple interpretations of reality that can differ across time and place but believe that these interpretations are in themselves a part of the scientific knowledge they are pursuing (Madill et al., 2000)

The aim of interpretivist research is to understand and interpret the motives, meanings, reasons and other subjective experiences which are time and context bound in human behaviour and social interactions rather than to predict causes and effects. This approach relies heavily on naturalistic methods (interviewing and observation and analysis of existing texts) (Ponterotto, 2005).

The main criticisms associated with interpretivism relate to the subjective nature of this approach and the potential for bias on behalf of a researcher, which in turn can undermine the ability of research findings to be generalised since data is heavily impacted by personal viewpoint and values (McEvoy & Richards, 2006).

3.2.3 Pragmatism- a third approach

This thesis will adopt a pragmatic approach to the research methods used in the collection and analysis of the data.

Pragmatists believe that the limitations and opportunities of the context in which the research is to be conducted are of most importance when deciding which method or methods are to be adopted (Silverman, 1993). It is important not to get tied up agonising over the opposing differences that different paradigms present but to use a pragmatic approach, responding to the strengths and weaknesses each approach can offer in answering the research question being posed (Patton, 2002).

Pragmatism is closely associated with research using both quantitative and qualitative methods known as 'mixed methods' (Creswell & Plano-Clark, 2007). The term mixed methods is used to refer to the use of a combination of two or more different methods that produce both quantitative and qualitative data in a single research project, which aim to provide a better understanding of the phenomena than either approach can achieve alone. (Johnson & Onwuegbuzie, 2004)

From a pragmatic perspective it can be argued that the nature of the research problem should dictate the choice of methods used. In many cases it is suggested that the most effective approach will be to use a combination of quantitative and qualitative methods or techniques (Olsen, 2002). Thus quantitative methods may be used to develop reliable descriptions and provide accurate comparisons, while qualitative methods can help to shed light on complex concepts and relationships that are unlikely to be captured by predetermined categories or standardised quantitative measures (McEvoy & Richards, 2006).

In this thesis, adopting a pragmatic approach will allow the interview data in chapter four to be treated as having equal status as expert knowledge in representing the issues faced by people who use medical devices in the home. The quantitative survey in chapter five will identify comparable patterns of practice and elaborate on the findings from the previous semi-structured interviews. The interview data from the longitudinal study in chapter six will be collected and analysed in terms of what is being said as a window on to real events, lives and emotions. It will then be discussed in terms of the underlying

social and psychological structures, acknowledging the social networks in which the participants are embedded. It is envisaged that adopting both quantitative and qualitative approaches will provide this research with a greater sense of balance and perspective.

3.3 Research strategies

This section will outline the research strategies used to answer the different research questions.

The subjective and experiential nature of the research questions "*How are medical devices integrated into the homes of users?"* and "*What is the lived experience of couples who are given a medical device to use at home and how does this change over time?"* were considered best answered using qualitative methods. There are different strategies to choose from in qualitative research which have different applicability and purpose, for example:

- *Participant observation* is an appropriate technique for collecting data on naturally occurring behaviours in their usual contexts.
- *Interviews* are an appropriate way of collecting data on individuals' personal perspectives, and experiences.
- *Focus groups* are effective in eliciting information concerning the broad overview of issues of concern to the cultural groups or subgroups represented in the group.

In order to obtain the personal experiences and perspectives of people who use medical device at home and in-line with previous studies in the reviewed literature, qualitative interviews were considered to be the most appropriate approach.

The question "*What do different groups of healthcare professions consider important in relation to home medical devices?"* is intended to look at the basic attitudes/opinions of different groups of healthcare professionals relating to the importance of different medical device characteristics and to compare the answers given by those different groups. In order to collect large amounts of

information from a large number of people that can be statistically analysed, a quantitative questionnaire strategy was considered the best approach.

3.3.1 Qualitative Interviews

Interviews are integral to much of interpretivist research and for this research were considered to be the most appropriate method help to capture the dynamic aspects of what people do, believe and think.

Interviews have been described as a form of conversation that are

> *"initiated by the interviewer for the specific purpose of obtaining research-relevant information and focused on content specified research objectives of systematic description, prediction or explanation"* (Cohen et al., 1989, p307).

Unlike quantitative strategies, qualitative interviews provide the opportunity to explore ideas or concepts (that cannot be directly observed) from the participants' point of view (Patton, 1980).

Interviews can take a variety of formats including unstructured or semi-structured. While unstructured interviews allow participants to talk about and focus the interview on issues that are important to them, semi structured interviews, while still allowing the opportunity to explore unanticipated or unexpected issues, allow data to be collected around *a priori* issues and topics (Smith et al, 2009). The qualitative interviews used in this thesis adopted a semi-structured approach to data collection.

In semi-structured interviews an interview schedule outlining open questions to be explored is used. Using this as a starting point the interviewer has the opportunity to modify the order in which questions are asked or indeed leave out an inappropriate question. There is also the ability to change the way that questions are worded and include additional questions or prompts should

unanticipated or interesting concepts be raised during the course of the interview.

Adopting a semi-structured approach can help in building up a rapport with participants, and by listening and responding appropriately, adopting a nonthreatening and non-judgemental manner can help to ensure that the data generated is as true a reflection of participants' views and opinions as possible (Smith & Osborn, 2008)

3.3.1.1 Adopting Thematic Analysis as a research method

Thematic analysis was adopted as the method that would be used for identifying, analysing and reporting patterns or themes within the data obtained from the qualitative interviews. While this method can organise and describe the data in rich detail it can also be used to interpret different aspects of the research topic (Boyatzis, 1998). What distinguishes thematic analysis from other qualitative approaches such as grounded theory or discourse analysis is that it does not rely on pre-existing theoretical frameworks and it is therefore a more accessible and flexible approach, able to be used with a wide variety of frameworks (Braun & Clarke, 2006). Thematic analysis can provide a rich thematic description of the whole data set which can involve some level of interpretation of the data but also provides clear links between themes and the aims of the study in order to substantiate any analytical claims. It is a useful approach when exploring under-researched areas and is particularly relevant to health service studies in being able to focus on individual experiences, people's views and opinions and people's practices (Braun & Clarke, 2014). It is for these reasons that thematic analysis was deemed an appropriate and useful method of data analysis for this research.

The study described in chapter four of this thesis uses Braun and Clarke's (2006) systematic approach to thematic analysis to identify, analyse and report the themes within the interview data.

A more in-depth approach to thematic analysis of the interview data described in chapter six was shaped and informed by Smith's (1996) interpretative phenomenology, which encourages a detailed examination of how people make sense of life experiences.

Philosophically, this approach is informed by the key theoretical approaches of phenomenology, symbolic interactionism and hermeneutics (Biggerstaff & Thompson, 2008).

Edmund Husserl, the founder of the phenomenological approach whose writing spanned 50 years, proposed the notion of intentionality. For Husserl, consciousness, which is central to being in and understanding the world, is always directed towards an object (Husserl, 1927). Husserl argued that in order to examine our everyday lived experience we must step outside our 'natural attitude' (the unreflective, common sense attitude we have as we live our day to day lives) and adopt a 'phenomenological attitude' (a reflexive move that redirects thoughts from external objects towards our internal perception of those objects) (Smith et al., 2009).

This work, in turn, Influenced the existential and phenomenological writings of Heidegger, Merleau-Ponty and Sartre, which rejects the Cartesian dualistic separation of mind/body, subject/object, and adopts the perspective of the human individual as an embedded, inclusive part of the world, in a particular historical, social and cultural context (Shineboure, 2011).

Heidegger uses the term '*Dasein*' (literally, 'there-being') to describe our very nature as being always somewhere, always amidst, located and involved in a world that it cannot be detached from. Thus individuals can only be understood as a function of their involvement with a world that itself can only be understood as a function of our involvement with it (Larkin, Watts and Clifton, 2006). In order to study a *'Dasein'* (existence) Heidegger proposes a 'hermeneutics of factual life' whereby reflection of a phenomena or individual life takes place through a lens of cultural and socio-historical meanings (Eatough & Smith, 2008).

Merleau-Ponty viewed our existence as embodied in the world which in turn led to the primacy of an individually situated world view:

> *"All my Knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless"* (Merleau-Ponty, 1962. p ix).

He makes the point that our sense of self is occupied in looking at the world as opposed to being subsumed within it. In this way the body should not be seen as an object in the world but as a means to communicate with that world. The notions of embodiment and subjectivity mean that while we may be able to observe and experience empathy for another individual, we can never truly share that individual's experience as it belongs to their own embodied position in the world (Smith et al., 2009).

Sartre, as with Heidegger, views the individual as engaged in the world but emphasises the developmental aspect of human being:

> *". . . existence comes before essence — or, if you will, that we must begin from the subjective. . . . What do we mean by saying that existence precedes essence? We mean that man first of all exists, encounters himself, surges up in the world — and defines himself afterwards. . . . He will not be anything until later, and then he will be what he makes of himself". (Sartre, 1946, no page number).*

This idea of 'becoming' brings to the fore the idea of individuals having the freedom to choose: "In one sense choice is possible, but what is not possible is not to choose. I can always choose, but I must know that if I do not choose, that is still a choice" (Sartre, 1946, no page number). These choices will inevitably lead us to encounters with others which are intrinsically stressful. The reason for this stress is this: I consider the world as my world made by my own self-

projection and organised around me yet the 'Other' claims the world as his own, made by his self-projection and organised around him. How then do I relate to this other and how does it alter and reshape my perception of the world? (Grene, 1971). This then can be seen as Sartre developing the idea that experience is also altered according to the presence or absence of others.

While this section has only been able to provide a cursory introduction to some of the ideas put forward by some of the most influential writers in phenomenological philosophy, the relevance to this approach is clear. The lived experience of any individual is complex and in order to gain some understanding of it requires an acknowledgement that individuals are embodied and engaged in a world of relationships, culture and objects and the resulting experience therefore comes from a unique perspective. The result of this is that attempting to understand an individual's experience of the world must involve interpretation of their reflections of their own experiences (Smith et al., 2009).

Smith's interpretative phenomenology is also informed by symbolic interactionism, which emerged in 1930s America. This theoretical movement, itself influenced by phenomenology, represented a rejection of the positivism found within the social sciences (Smith, 1996). Its intellectual roots can be traced back to include the contributions of William James, George Herbert Mead, and John Dewey among others and it is concerned with the social nature of human life and behaviour (Denzin, 1995).

According to Blumer (1986) symbolic interactionism rests on three simple assumptions. First, individuals act toward things on the basis of the meanings that those things have for them. Such things may include not only physical objects but also other human beings (either as individuals or as different groups), institutions and ideals (i.e. independence or honesty). Second, the meaning of such things arises out of the social interaction with others. Third and finally, meanings are modified through an interpretative process which involves individuals symbolically interacting with one another.

Symbolic interactionism has many strands but common to each is that instead of passively perceiving an objective reality, individuals understand and interpret their world, creating their own life stories. This presumes that the individual is the final authority in their subjective experience but any understanding of those experiences can only be obtained through the process of interpretation (Denzin, 1995).

Another major theoretical touchstone is that of hermeneutics. Originally devised as an attempt to help make clear or more acceptable obscure passages of religious texts, it developed as a philosophy concerned with interpretation itself and has underpinned the interpretation of a wide range of literary works (Smith et al., 2009).

For Schleiermacher in the early 1800s understanding was seen as an art of reverse composition or the re-experiencing of the text author's mental processes. Thus interpretation can be seen as two interacting moments: the *grammatical* (objective textual meaning) and the *psychological* (the individual life of the author) (Palmer, 1969).

For Heidegger the task of phenomenology is to uncover or reveal that which is hidden and in order to achieve this he puts forward the concept of a hermeneutic phenomenology in that access to an individual's *Dasein* is always through interpretation (Shinebourne, 2011). However, the interpreter is also amidst and part of the world and therefore brings to the interpretation preconceptions, assumptions and prior experiences that can never truly be 'bracketed off', which is at odds with the phenomenology of Husserl (Smith et al., 2009). These preconceptions may not be obvious in advance and may only come to light during the interpretative process. This results in a dialogue between what the text brings to us and what we bring to the text (Shinebourne, 2011). Thus, in attempting to get close to an individual's personal world, to get what Conrad (1987) calls an 'insider's perspective' a double hermeneutic is involved. This means that as "participants are trying to make sense of their world: the

researcher is trying to make sense of the participants trying to make sense of their world" (Smith and Osbourne, 2003 p53).

Drawing on these theoretical approaches an interpretative phenomenological approach to thematic analysis is concerned with a detailed understanding and exploration of the human lived experience and involvement in the world. Its commitment is to describing, interpreting and putting in to context how individuals make sense of their experiences. As such it was considered particularly appropriate as it offered a way of exploring not just the lived experience of being given an oxygen concentrator but also how couples made sense of this over time.

3.3.1.2 Quality in qualitative research

It is difficult to judge the quality of qualitative research within the traditional framework used by quantitative research. There is a major debate as to whether the principles of generalisability, validity and reliability, which are deeply rooted within positivist research, should or can be effectively applied to studies adopting a qualitative interpretative approach due to differences in epistemological, philosophical, and methodological perspectives. However, it is none the less important that practitioners and policy makers are able to have confidence in this type of research (Dixon-Woods et al., 2004; Meyrick, 2006). Part of the problem of defining the criteria by which to judge qualitative research is due to the tendency to treat qualitative research as a unified field, where in fact it may be more useful to consider quality in light of the particular method of data collection and methodological approach being used (Dixon-Woods et al., 2004). Some broad principles for assessing qualitative research have been proposed by Yardley (2000). These principles are *sensitivity to context*, *commitment and rigour*, *transparency and coherence*, and *impact and importance*. Lincoln and Guba (1985) recommend respondent validation where participants are asked to check researchers' interpretations. Creswell and Miller (2000) suggest an independent audit where the process and narrative account is verified by someone who was not part of the research.

Following a review of the literature Meyrick (2006) devised a framework for assessing the rigour or quality (in terms of credibility and trustworthiness) of qualitative research that attempts to be inclusive of a range of research techniques. It builds on two key common principles of good qualitative research, namely, transparency and systematicity and it is this framework that will be used in relation to the qualitative studies in this thesis.

The framework can be broken down into the following 6 steps:

Researcher theoretical stance- Good quality research ensures that the theoretical stance of the researcher is stated clearly in the study. In relation to the qualitative studies in this thesis this chapter has set out the pragmatic stance of the research.

Methods- the aims and objectives of the research, research question and selection of appropriate methods should be clearly set with reference to a body of literature. In this thesis the literature review has set out the objectives and research questions and this in turn has informed the appropriate methods.

Sampling- A key element of qualitative research is to ensure there is sufficient detail about sampling techniques and participant group information. The sampling and participant information will be set out clearly in each relevant chapter.

Data collection- Good qualitative research should include sufficient detail about how the data were collected such as a description of the context and how/why any changes in techniques or focus were made. Again, each chapter will provide detailed information on how and where data was collected

Analysis- Providing sufficient information about the journey from data to conclusions is particularly important. The reader should be given sufficient detail to be able to follow the process. Step by step details of how the thematic analysis was carried out will be presented in the relevant chapters.

Results and conclusions- Demonstrating exactly how the data themselves shaped the conclusions is important in reinforcing the link between data and conclusions in qualitative work and is demonstrated by providing excerpts from participants. Giving their transcripts or conclusions back to the participants or an independent audit are ways of establishing the strength of conclusions and verifying the trustworthiness and credibility of the findings. The results from each of the qualitative studies will contain extensive excerpts from the data to inform discussion around the findings and subsequent conclusions. Independent audits of the analysis were carried out on both qualitative studies (chapters four and six). This involved handing over any paper notes and/or digital output generated during the data analysis along with the research findings and final themes and sub-themes in order that the independent researcher could examine both the process and narrative account in order to verify the trustworthiness and credibility of the findings. In both cases the auditor was an experienced qualitative researcher who was not involved in these studies.

3.3.1.3 Qualitative interview participants

Qualitative studies are different to quantitative studies since they aim to identify qualitatively similar or different patterns in a data-set rather than to quantify magnitudes. Thus the numbers of participants included in a study is generally less important than selecting appropriate participants based on the scope of the study, the nature of the topic and the quality of the data (Sandelowsk, 1995; Morse, 2000).

It was felt that with regards to the qualitative interviews it was important to select participants that were likely to be affected by medical device use in the home in order to capture issues that were important to them.

It is estimated that around 15 million people in England have a long-term condition and that those conditions are more prevalent in older people (58 per cent of people over 60 compared to 14 per cent under 40) (DoH, 2012) and as such, older people are increasingly becoming a major group of home healthcare device users (Bitterman, 2011; Kane et al., 2005). This indicates that older people

with a chronic illness are a group of people for whom this research may have greater relevance.

As people get older, the immediate home environment becomes more important and a number of reasons have been identified for this (Oswald & Wahl, 2005). The length of time spent living in a certain place of residence might have an impact on the meaning of home and most elderly people wish to live in their own home for as long as possible with many continuing to live in residences they have occupied for most of their adult lives (Law & Warnes, 1982). The immediate home environment is the primary living space in old age, with older people spending more time at home than younger people due to illness and retirement. In fact it has been suggested that older people (65 years and older) spend on average 80% of their daytime at home (Baltes et al., 1999). It has also been suggested that the presence of souvenirs, pictures and precious memories which are accumulated over the years that increase the meaningfulness of the home for older people (Vikko, 1996).

In summary, as a result of the increasing presence of medical equipment in the homes of older people to treat and monitor chronic conditions, and the growing importance of the home environment for older people, it was felt that this age group would be the most appropriate participant group to focus the interviews on.

Researchers of this particular age group have tended, as has 20th century society in general, to accept the government's ‘pension age’ or ‘retirement age’ as the accepted dividing line between mature adulthood and old age (Roebuck, 1979). At the time of writing the default retirement age in the UK of 65 has been phased out and most people can work as long as they wish. The state pension age, i.e. the age a person can claim their state pension based on national insurance contributions, ranges from between 61 and 68, depending on when someone was born and if they are male or female. For the purposes of this thesis the term older people will be used to refer to people aged 65 or over unless otherwise

stated. This age has been chosen as it is consistent with other research and allows for comparisons across findings.

It is important to emphasise that this thesis does not assume that older people are a homogenous group only that the literature suggests that any impact that home medical devices have on the home environment might be more keenly felt by this particular group.

3.3.2 Quantitative questionnaire

In order to answer the question "*What do different groups of healthcare professions consider important in relation to home medical devices?"* addressed in chapter five, a quantitative questionnaire approach was considered the most appropriate strategy.

The term 'questionnaire' has been used to describe a variety of data collection instruments that are frequently used to collect primary quantitative data from patients and healthcare professionals and has been defined as:

> *"Structured schedules used to elicit predominantly quantitative information, by means of direct questions, from informants, either by self-completion or via interview" (McColl et al., 2001 p3).*

Quantitative surveys aim to convert the information they collect to meaningful numbers (e.g. counts, averages, rates) relating to the population of interest in terms of what Dillman (1991) described as:

- Attributes –what people are.
- Behaviour and events – what people do.
- Beliefs/knowledge – what people think is true.
- Attitudes/opinions/reasons etc. – what people say they want or how people feel about something.

Respondents' scores in relation to the answers to survey questions can then be analysed by summarising or applying statistical tests whereby inferences can be

made from the sample on which the data were collected to the underlying population.

Questionnaires can be administered in different ways, for example: face-to-face, via the telephone or internet, or sent out to potential participants via the postal service. Responses to questions can be recorded by the researcher or the respondent (self-completion questionnaires) using “pencil-and-paper” or computer assisted techniques (McColl et al., 2001).

The aim of this research is to use a quantitative questionnaire to gather valid, reliable, unbiased and discriminatory data from different groups of healthcare professionals and non-professionals in order to compare their attitudes or opinions towards home medical devices. as such, the use of a questionnaire was deemed the most appropriate tool by which to achieve these aims.

3.3.2.1 Quality aims in questionnaire research

The key aims of quantitative questionnaires are to collect information that is: valid, reliable, unbiased and discriminating.

Validity can be thought of as the extent to which a particular concept is accurately measured in a quantitative study. This can be broken down in to three major types. A questionnaire should: accurately measure all aspects of a construct (content validity), measure the intended construct (construct validity) and extent to which questionnaire is related to other instruments that measure the same variables (criterion validity) (Heale & Twycross, 2015)

Reliability refers to the accuracy of a quantitative study. In other words, the extent to which a research tool consistently reproduces the same results if it is used in the same situation on repeated occasions (Heale & Twycross, 2015).

A quantitative questionnaire should also strive to be free from bias, that is, free from features that may distort the design, execution, analysis or interpretation of the research (Sackett, 1979).

Questionnaires should also be able to distinguish adequately between respondents for whom the underlying level of the concept is different (Steen & McColl, 1996).

The inability to probe responses is a particular disadvantage of questionnaires compared to semi-structured interviews. Questionnaires are structured instruments that allow little flexibility to the respondent with respect to response format. In essence, they can often lose any nuance or depth of meaning in a response (i.e., respondents often want to qualify their answers). This can be partially overcome by allowing space for comments. Comments can usually help provide insightful information that would have otherwise been lost (Oppenheim, 2000). For this reason the questionnaire developed in chapter five will include open questions.

3.4 Summary

This chapter has presented a general account of the research philosophy, and outlined the strategies that will be used to conduct this research. The research presented in this thesis takes a pragmatic view acknowledging the position of both the positivist and the interpretivist camps by utilising a mixture of qualitative interviewing and quantitative survey. The practical aspects of each research method selected will be explained in greater detail in the relevant chapters.

Chapter 4: An exploratory study looking at the integration of medical devices into the home environment

4.1 Introduction

This chapter presents the results of a qualitative interview study and the implications of this study for this research. The aim of this study was to begin to answer the research questions posed at the end of the literature review in chapter two and in particular explore the question:

How are medical devices integrated into the homes of users?

Previous work has described users' interaction with medical devices in the home mainly in relation to the physical characteristics of the environment. This study will extend this work by exploring how these devices may impact on the different 'aspects of home' proposed by the literature.

4.2 Methods

4.2.1 Participants

Ethical approval for this study was granted by The University of Nottingham Faculty of Engineering Research Ethics Committee. The aim was to recruit a sample of 12 participants from the East Midlands. This was considered appropriate as it was similar to previous literature in the field e.g. Lehoux (2004), Fex et al. (2009) and Avril-Sephula et al. (2014). As discussed in chapter three, For reasons of appropriateness in terms of relevance to chronic conditions and the increasing importance of the home environment, the inclusion criteria were that participants had to be 65 years or older and they had to use one or more medical device in the home. All participants had to be able to consent to taking part and interact verbally in English. The age of the 12 medical device users interviewed ranged from 65 to 83 years (mean 72 years) and 6 were female.

For reasons that will be discussed later, seven of the interviews also included input from partners of the interviewees. In order for partners' data to be included an amendment to the ethics approval was sought and gained after the start of the study. The age of the 7 partners ranged from 65 to 82 years (mean 72) and 4 were female (see table 4.1).

Device user pseudonym (age)	Devices and duration of use	Partner present	Partner pseudonym (age)
Ann (67)	Transcutaneous Electrical Nerve Stimulation device > 1year Leg circulation booster < 1year	Yes	Adam (69)
Brian (69)	Blood pressure monitor >5years Blood glucose meter >5years	Yes	Beryl (65)
Cath (77)	Oxygen concentrator 8 months Portable oxygen tank 1 year Nebulizer >1year Stair lift >2years	Yes	Carl (74)
Derek (75)	Continuous Ambulatory Peritoneal Dialysis 4 years Automatic Peritoneal Dialysis 8 months	Yes	Debbie (77)
Emma (73)	Blood pressure monitor 6 years	No	N/A
Frank (75)	Implantable Cardioverter-Defibrillator monitor 6months	Yes	Florence (72)
Gale (80)	Transcutaneous Electrical Nerve Stimulation device 3months Telecare monitor >10 years	No	N/A
Hayley (83)	Stair-lift >3 years	Yes	Harvey (82)
Ian (67)	Nebulizer >3 years	No	N/A
Jack (69)	Nebulizer >5 years Blood pressure monitor >5 years	Yes	Jill (67)

	Sats monitor >3 years Blood glucose meter >3 years		
Kevin (66)	Blood pressure monitor 8 years	No	N/A
Lily (65)	Blood pressure monitor 1 year Mobility device 2 years	No	N/A

Table 4.1 Study 1 participant table

The definition of a medical device was taken from the Medicines and Healthcare products Regulatory Agency (MHRA) which is an executive agency of the United Kingdom Department of Health. The MHRA describes the term 'medical device' as covering *"all products, except medicines, used in healthcare for the diagnosis, prevention, monitoring or treatment of illness or disability"* (MHRA, 2014b). This broad definition of medical device was used in order to capture the experience of older people with a wide range of medical devices.

In order to capture the 'home' aspect of home use medical devices and limit some of the variability inherent within the term, participants were excluded if they lived in care/nursing homes. It was thought that medical devices in these types of establishments would be more readily accepted and be considered normal for the surroundings.

4.2.2. Recruitment

Gaining access to potentially vulnerable groups (such as older people) for the purposes of research can be particularly difficult (Sutton et al., 2003).

Recruitment initially started by advertising the study with posters placed on the campus of the University of Nottingham and in targeted locations where they would likely be seen by older people such as Post Offices, shops and churches. Advertisements were also placed in the local press. While these approaches were not entirely fruitless the uptake was disappointingly low.

A different approach was then taken, which involved approaching patient and older people's groups. This required a great deal of negotiation with gatekeepers to access these groups. Gatekeepers provide an important function and act out of genuine concern for the potential participants' well-being and can protect some of the more vulnerable members from unsolicited contact. However, it has been recognised that gatekeepers can also strongly influence participants to participate in research or not, especially those people who rely on others to help them make decisions that may impact on commitment and time (Miller et al., 2003; Resnick et al., 2003). Some of the responses received about the study were not particularly helpful. For example, some groups that were contacted replied that they thought that their members would not be interested and that they saw little point in putting it to their membership. The main solution to this barrier involves good communication between the researcher and potential gatekeepers with special attention given to educate family members of any risks and benefits of the research as obtaining their understanding is crucial (Ridda et al., 2010). While this was attempted, opportunities to establish a rapport with gate keepers were limited.

A number of national charity groups were approached and these required the study proposal to be reviewed by their senior management before details about the study could be distributed via their newsletter.

The recruitment method that proved the most fruitful was snowball sampling. Snowball sampling is when the researcher accesses participants through contact information that is provided by other informants and is an often used tactic to reach 'hidden' or marginalized populations (Noy, 2008). Snowball sampling offers practical advantages where studies are primarily explorative, qualitative and descriptive (Atkinson & Flint, 2001), however, it has been suggested that this method can lead to problems of representativeness and selection bias, particularly in quantitative studies (Van Meter, 1990). In the present study the wife of one participant in the study was an active member of the community and other people contacted us to participate in the study as a result of her recommendation.

Potential participants who contacted the author with a view to taking part in the study were given a verbal outline of what was involved and how issues around anonymity and confidentiality would be addressed, which mirrored the information given in the participant information sheet. A time and date convenient to the participants to take part in the study was agreed upon and contact details recorded. It was made clear to participants that they could change their minds about taking part in the study at any time and could just send a message to the researcher that they did not want to keep this appointment. This allowed a 'cooling off' period, which aimed to prevent participants from feeling pressured in to taking part (Holm, 2011). Participants could choose where the interviews would be conducted. They could choose to come to the University, pick a neutral place such as a café or the interviewer could visit them at home. Two participants chose to be interviewed at the university and the remaining ten participants chose to be interviewed in their own home. It was acknowledged that for anyone, particularly older people, inviting strangers into your house can be a source of anxiety, especially if you feel vulnerable or live on your own. Because of this, all interviewees were offered the option of having a chaperone present during the interview; however, none felt they needed this provision. In addition, the safety of the researcher had to be considered and the University of Nottingham lone working procedure was implemented (University of Nottingham, 2013). Participants received an inconvenience allowance of £10 worth of shopping per interview.

4.2.3 Procedure

At the beginning of each interview the researcher took some time to put the participants at ease with small talk. Participants were then asked to read a participant information sheet that explained the study and what was required from them if they decided to take part. Information was also provided about confidentiality, data storage/disposal and the right to withdraw from the study and to have their data removed from the analysis. This information had also been given verbally to the participant during their first contact with the

researcher. The combination of an information leaflet and prior verbal explanation can result in a better understanding of various elements of a study that are prerequisites to gaining valid consent (Freer et al., 2009). It was emphasised to participants that they would remain anonymous and any statements made during the interview would be untraceable to a given individual as pseudonyms would be used. A consent form was completed (including the partner where appropriate) to ensure understanding of these issues and to confirm that participants were willing to continue.

The semi-structured interviews were guided by an interview schedule consisting of 11 open ended questions which allowed for more focused prompts if required (see appendix 1). The interview began with questions regarding the devices themselves (e.g. usage and storage). This was followed by questions about the participant's home. The final part of the interview encouraged participants to consider how they felt about the device, how their life and identity has changed since owning the device and what, if any, changes they would make to the device. A semi-structured interview technique was selected as it is well suited for exploring the opinions of respondents regarding complex and sometimes sensitive issues. It also enables the interviewer to probe for more information and clarification of answers (Barriball & While, 1994).

While the interview was guided by an interview schedule, the style of the interview was deliberately made to feel more like a social encounter. This style of interviewing can help break down the barriers between interviewer and interviewee, which is ethically congruent with the empowerment of vulnerable groups and encourages participants to speak openly (Russell, 1999). While this particular interview situation suggests an egalitarian status for both the interviewer and the interviewee, this may not reflect the actual case because of the power imbalances in the interview methodology (Anyan, 2013). The power of the interviewer lies in their authority as a seeker of knowledge and expertise, and that of the interviewee as a privileged knower with the exercise of power ebbing and flowing throughout the duration of the interview (Nunkoosing, 2005).

When participants were interviewed in their own home their partner or spouse was often present during the interview. In keeping with the interview as 'social encounter' approach, it would have been awkward (not to mention an ethically difficult situation) to have had to exclude a person from a room in their own house. The partners that were present showed more than a passing interest in the study and were keen to listen in on the interview, so it was left to the participant to decide whether the partner stayed in the room while the interview took place. When partners were present, however, they were not silent observers; while questions from the interview schedule were directed at the users of the medical device, the conversational style of the interview enabled partners to contribute, what turned out to be rich data, to the study. This supports previous research that has shown that long-term couples can provide richer, more vivid descriptions of autobiographical events when interviewed together compared to individually (Harris et al., 2014). As a result of this event an amendment was submitted to the ethical committee to enable partners to participate in future interviews. Data from a partner that was collected during an interview prior to securing the amendment was not used in the analysis.

Interviews lasted approximately 60 minutes and upon completion interviewees were given a full de-brief with contact numbers for places of further support in case they were required. The interviews were recorded digitally and were subsequently transcribed verbatim.

4.2.4 Analysis

Braun and Clarke's (2006) systematic approach to thematic analysis was used to identify, analyse and report the themes within the interview data. According to their method, thematic analysis can be divided into 6 separate stages.

Stage 1: involves engagement and familiarisation with the data. Each transcript was printed out and read several times. Reading the transcripts on paper as opposed to the computer screen was a personal preference as it made it easier

for initial notes to be made about ideas for coding and identification of possible patterns.

Stage 2: involves the systematic generation of initial codes: "the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998, p63). From this point on, the transcripts of the interviews were copied into NVIVO 9 software data management system (QSR international Pty Ltd., 2010). The use of this software was again personal choice in that it made managing and keeping track of the data easier. It is acknowledged, however, that tools such as these may have a mediating effect between the analyst and the data, revealing some things of interest while hiding others (Blandford, 2013). The study took a data-driven, inductive approach to coding the data which allowed for an overall description that was strongly linked to the data itself rather than coding the data while trying to fit it into a pre-existing coding frame (Patton, 2002).

Stage 3: completion of the previous stage resulted in a long list of different codes from across the data set. This third stage refocused the analysis at a broader level of combining and sorting these codes to produce potential themes that best "capture the essence of the phenomenon under investigation" (Madill & Gough, 2008, p258). Relationships were sought between codes, between themes, and between different levels of themes (e.g., main themes and the sub-themes within them). While some codes went on to form themes in their own right, others that did not appear to fit anywhere were discarded or temporarily put to one side. Using computer software made it easier to move codes around and try different things out while keeping all the extracts of data 'attached' to the codes for reference.

Stage 4: once a preliminary set of themes had been devised the next step was to revisit and refine those themes. Patton (2002) suggested that themes should have 'internal homogeneity' (i.e. that their constituent codes should have a meaningful commonality) and an 'external heterogeneity' (i.e. that the themes

themselves should be different and distinct from other themes). In line with this approach, some provisional themes were judged not to be themes while others were absorbed into other themes. It was also an opportunity to code any additional data that has been missed in earlier coding stages.

Stage 5: entailed the generation of clear definitions and relevant theme names. Theme names were chosen that captured the essence of what the theme was describing and how the different themes combined to produce an overall narrative in relation to the research question.

Stage 6: involved the selection of data extracts that best demonstrate and illustrate the analytic narrative that can be used to support the research findings.

4.3 Results

Four main themes were identified which illustrated the transition and challenges faced by users following the introduction of home use medical devices. These themes were: 'Striving to maintain control'; 'Evoking different emotions'; 'The accommodating home'; and 'The social device'. The results are presented as main themes and sub-themes (see figure 4.1) substantiated by extracts from participant interviews. The extracts were chosen on the basis that they best illustrated the themes

Main theme	Sub themes
Striving to maintain control	*Time costs* *Not having a choice* *Personal control*
Evoking different emotions	
The accommodating home	*Finding a place in the home* *Making changes*
The social device	*Disrupting social harmony* *Bringing people together*

Table 4.2 Main and sub themes from participant interviews

4.3.1 Theme 1: Striving to maintain control

The use and provision of medical devices did not come without some cost to the user. Users described different way in which their feelings of control over their lives were both supported and undermined.

4.3.1.1 Time costs

When using a device there are two ways that participants deem time as a valuable resource. The first is the time taken for the device to deliver the treatment:

> *"You've got to remember that [participant 10]spends three quarters of an hour in there[on his device], morning and night and if he does it four times a day, it's three or four hours a day so it's a lot" (Jill).*

> *"Well I should be on 15-16 hours but it doesn't work out like that, it works out at about 11 or 12" (Cath).*

> *"I mean, when I first started on[a nebulizer], it would take 20-25 minutes, that it went to 15 minutes, then they got down to the ten minute one. Then with the little one I had, I was under four minutes. I'm now back on the bigger one, which is ten minutes" (Ian).*

The second time expense associated with medical devices is maintenance and setting up:

> *". . . and just the sheer effort of putting the whole lot together, it took quite a while out of the day . . . it seemed to take one great chunk out of the day you didn't want it to" (Derek).*

"The problem with the little [nebulizer] was, dust. It sucked up a lot of dust. So you had to be forever hoovering it out to make sure it was clean" (Ian).

The time spent interacting with these devices reduced users freedom to get on with their other daily activities. The devices dictated not only the time spent on them but also when and how users' other time around the home could be spent.

4.3.1.2 Not having a choice

Some participants considered that using medical devices was just something you had to do and were very conscious of the potentially fatal consequences of not using them. There was a sense of resignation and powerlessness surrounding their illness and device use:

"There is no alternative so you take what comes at you . . . it doesn't make you very happy but that's your fate and I've got you know, kismet" (Derek).

"We don't really have a choice do we? Because if Jack didn't have all these things, he probably wouldn't be around" (Jill).

"But you've gotta do it. If you don't do it, you won't be doing it. . . . You realise you've, it's a fact of life, you've gotta do it" (Ian).

In order for participants to benefit from using a medical device, the idea of choosing the best device for them had to be sacrificed. Many participants, who were given devices by the hospital or doctors, reported not having been given a choice of device at all:

Interviewer "- but were you presented with a choice of nebulisers or a choice of concentrators?"

"No" (Cath). . . "No, not at all" (Carl).

Interviewer: "Okay. So do you have any choice over the type of device?"

"No. . . . They've gone to what I call cheap and cheerful - because it was too expensive really for them to service them or repair them" (Ian).

A similar reporting of limited choice was made by those that had purchased the device themselves from local pharmacies:

"Well to be perfectly honest, it was the only one that was on the shelf at the time" (Jack).

"I went into [the chemists] and looked around them all . . . there were two or three there so I asked a lady about it" (Lily).

Participants reported that not only did they have no control over their need to use medical devices and failure to use devices would have been detrimental to their health but also that they were denied the opportunity of choosing a device that might be more suited to their own personal circumstances.

4.3.1.3 Personal control

Different strategies were used by participants to enhance and maintain levels of personal control that may have been reduced as a result of feelings of powerlessness associated with the lack of choice of using a device. Participants reported the importance of using devices to monitor their condition and how this enhanced their feelings of control:

"Well, I use my [glucose] monitor seven or eight times a day probably. . . .That's so I can just, I always know what state my blood sugar's in" (Brian).

"[With my blood pressure monitor] I feel in control of managing the high blood pressure I think, and I know what

it is. . . . You're not in control if you don't have some way of measuring it yourself" (Kevin).

Some participants compared themselves to other device users who were not as in control of their situation or did not use the device correctly:

"And it's amazing the number of people I've met who know absolutely nothing about [diabetes] and they're sitting there and we got talking about it and they know virtually nothing about what's what, the situation they're in . . ." (Brian).

"There are people that have got [telecare emergency buttons] here and they leave them on the sideboard or the kitchen cabinets, they forget to put them on . . . a very close friend had a fall in her bathroom – she didn't live here – had a fall in the bathroom and she hadn't got it on. She died" (Gale).

Participants compared themselves to others and highlighted their own mastery over the device. The importance of this mastery and its positive effect can be seen in the sense of pride expressed by some of the interviewees:

"You've got to know how to use the equipment. Luckily I've been shown properly and I've always used it in the correct manner and it's always worked" (Jack).

"[It is important to] Make sure you do it properly. Make sure you are relaxed when you do it and make sure you know exactly what you are doing . . . so make sure that you've read the little booklet that goes with it so you know exactly what they mean and what they don't mean" (Lily).

This showed that mastering the device was a way of regaining some control over use of the device. While users may not have control over whether to use the

device or the type of device they have to use, at least they were able to exert some control over their situation by becoming experts at using their own devices.

4.3.2 Theme 2: Evoking different feelings

Medical device use was associated with a variety of emotions. Negative feelings around device use included anxiety and annoyance:

> *"I suppose I'm always a bit anxious about first getting on [the stair lift]" (Hayley)*

> *[when they delivered the oxygen concentrator] I was frightened, yes I will be honest, I was frightened, yes. . . . Because I just didn't know what to expect" (Cath).*

> *"I don't want to be ill; I don't want to have problems. So having to do that [monitor blood pressure] just reminds me that I've got them. And that annoys me" (Lily).*

Device use was also linked to positive emotions such as peace of mind and confidence:

> *"[it is]know[ing] exactly what my [blood sugar level] is which gives you peace of mind really" (Brian).*

> *"Yeah, [using my devices] it gives you confidence. If you know things are working and you're doing them right then you can benefit from it" (Jack).*

> *"It gives me a sense of security that I've got it beside me to use' (Ian).*

> *'Yeah, it does help; it puts my mind at ease" (Lily).*

For these participants the positive emotions seem to stem from the trust they had in their devices which made them feel safe and secure.

For one participant it provided a feeling of liberation and freedom:

> *"[The blood pressure monitor] has made me live each day as it comes, and make the most of it" (Brian).*

Some participants reported feelings of detachment concerning the device, describing the device as being' adequate' and a tool for serving a particular purpose:

> *"This [blood pressure monitor] seems absolutely adequate for my purpose" (Ian).*

> *"Yes, I mean it's just an instrument as far as I'm concerned. I don't have any attachment to it" (Emma).*

4.3.3 Theme 3: The accommodating home

Introducing a medical device into the home environment is not without its problems. Sacrifices and changes need to be made to the function and looks of the home which may not have been anticipated.

4.3.3.1 Finding a place in the home

The physical properties of some devices determine how and where they can be used in the home:

> *"[The oxygen concentrator] it is like a bedside cabinet which is in steel. . . . [I]t's extremely heavy. . . . [and] it's in the middle bedroom because it's so noisy" (Cath).*

> *"[If the nebuliser was smaller] you could move it to the side of your bed when you weren't well. Whereas you say to me, "Oh don't move that thing, it's too big" don't you?" (Jill).*

One participant noted how his wireless telehealth monitor interfered with other equipment in the house:

"The thing is it interferes with my laptop, if I want to send an email to our friend I have to unplug it because the internet won't come up while it's still plugged in for some reason" (Frank).

While some devices are prescriptive regarding where they can be used:

"It says the ideal place is at your bedside and it says in there, so it is at my bedside and I've got no qualms about that" (Frank).

Others required certain conditions and so are used where it was most convenient:

"Just in the kitchen really because there's a convenient table at the right height" (Kevin).

The majority of participants mentioned the device in relation to the bedroom, with one participant relating this to feelings around privacy and intimacy:

"[I take my blood pressure in the bedroom] because that's where I'm usually undressed and it's a sort of more intimate thing, I suppose. Anywhere else, it's [in]appropriate because it's an intimate . . . So it's my bedroom and it's a very personal thing to me" (Emma).

4.3.3.2 Making changes

Sometimes the home has to be physically altered to accommodate the device and associated equipment. Some of the time these alterations have to be carried out by the users:

"Yes, this hall . . . where we've got cupboards now was rows of shelves from floor to ceiling with bags or boxes of dialysing fluid" (Derek).

"The front bedroom of course has totally changed now. . . . It's basically my respiratory room really" (Jack).

"[When they fitted the concentrator] they just draped piles of pipe across the bedroom, round the bed, and left it at the side. . . . So I got some steel from bits in the shed, and I made a pole that goes up and an arm out . . . so Cath gets in bed and it hangs straight down and she can turn over, she's more or less free with it" (Carl).

This theme illustrates that every home is different and that devices cannot and do not just 'fit in' to an environment. The couples had to find different ways to make them fit in.

4.3.4 Theme 4: The social device

Home use medical devices are not used in isolation and as such participants reported the various effects that using these devices had on family members and others.

4.3.4.1 Disrupting social harmony

Some participants reported that device use had a negative impact on their partners which meant having to use the device in private:

"At first it was a little bit of a problem between my husband and I because he kept on saying, "Why do you keep on taking your blood pressure?". "The doctor told me". "You don't have to keep taking …". So I now do it usually when he's not around. I don't know why he gets uppity about it, but it seems to make him feel a bit annoyed that I keep doing it" (Lily).

It seems that Lily's husband felt particularly uncomfortable seeing her take her blood pressure. While the reason is unclear it could be that reminding him of his

partner's illness evoked feelings about death and dying as Lily noted he was understandably worried about her on-going health concerns.

Another participant who used a device overnight explained some of the problems with sleeping arrangements and alarms going off:

> *"The problems [my wife] had I think [were] more than me at night with a buzzer going off" (Derek).*

> *"If I got to the point where I was exhausted, I would have, yes, I would have slept in a separate bedroom on occasion to get an undisturbed night. . . . And we had to change sides because of the way the bedroom is laid out and the best way to do it was to have it on what is my side. So we had to change sides. That was strange" (Debbie).*

Having spent many years sleeping together in the same bed, having to sleep apart or even swapping sides of the bed was particularly difficult. Most people have particular bedtime routines that can be unsettling when they have to be changed and can take some getting used to.

While some interviewees were happy to use their device in front of others using the device in public was deemed to be problematic for some:

> *"[using the device in public] . . . I could see the anxiety on their faces. "Is he all right?" . . . so I stopped doing it. Went and hid myself and did it on my own" (Ian).*

Not all influences on others were negative; one participant commented on how the device, as a symbolic reminder of her illness, had brought herself and her daughter closer together:

> *"So she's realised mum isn't quite so invincible and mum is going to go one day and what have you so it makes her … in a way it makes her love me a bit more" (Lily).*

4.3.4.2 Bringing people together

It was not uncommon to find that people were willing to share their device with others and that the devices themselves became accepted and part of family life.

Devices were shared with family members:

> *". . . like my son-in-law had when he had a bad back he used . . . the TENS machine, [which] means he can drive home" (Ann)*

> *". . . and I did let my sister have, yeah, she had a go at [the stair lift], because she's got a problem with her back or knee" (Hayley).*

It also seems that both the user and partner had adopted joint ownership and responsibility for the devices as when partners were talking they used the pronoun 'we':

> *"And we've got a standby cylinder for the inhaler … for the concentrator, if there's a power failure" (Carl).*

> *"I said that we couldn't wait three years because we wanted a shower and not a bath" (Jill).*

The use of medical devices was not hidden from young grandchildren and became part of the interaction between the grandchildren and their grandparents:

> *"My grandchildren love it because they have a go on it when they come out and do their blood pressure. They have a little book that I keep their blood pressure in when it's done" (Lily).*

"Yeah, well, yeah, yeah, he just says you know, "Granddad, what are you doing? Oh you're doing your injection, are you? Let me watch" (Brian).

4.4 Discussion

It is clear from the results that using medical devices in the home presents challenges to couples in terms of how the device is adopted and the adaptations that they are required to make both personally and environmentally.

The theme *striving to maintain control* emphasised some of the ways having a home medical device undermined people's ability to choose or control different aspects of their home life and is related to the 'promotes a sense of control' aspect of home set out in the working model described in the literature review (chapter two).

The users of the medical devices were left with little choice about using the device to monitor or treat their medical condition as to do otherwise would be detrimental to their medical condition. Furthermore, there was limited choice over the particular type or make of device that they were given to use.

A perceived lack of choice or control over the details of a person's everyday life can be damaging to physical and mental health and is positively associated with mortality (Langer & Rodin, 1976; Shultz, 1976). The situation reported by participants in the current study suggests that having to use a medical device at home puts their sense of control in jeopardy.

The home should be the place where we are most in control, where people have the power and freedom to make their own choices and actions (Despres, 1991; Sebba & Churchman, 1986). A distinctive aspect of home compared with any institution is that those who live there are in charge of decisions about what is brought into the home and what happens in the home and when. Thus people who may already feel powerless by illness may suffer the additional indignity of not being allowed to make decisions that have consequences on their own home

(Heywood, 2005). The aspect of home as being a place where you are free to act autonomously i.e. to go where you want and do what you want for yourself, was also affected due to the time constraints placed on couples by the devices.

The home medical device also presented opportunities for participants to exert control in their lives. According to Taylor (1983) part of the adjustment process to a threatening event (e.g. chronic illness) is control or 'mastery' over the event, in order to manage the condition and express a sense of personal control. This control can be achieved by taking active steps to control the illness itself. This study found that participants are using their device to have control or mastery over their situation by monitoring their condition and using the results to modify behaviour. For example, Brian checked his blood glucose seven or eight times a day so that he could adjust what he ate to keep his blood glucose levels within the desired range. Another expression of mastery can be achieved by assuming control over related aspects of an illness such as treatment and becoming an expert in how to use the device itself.

The theme *evoking different emotions* highlights the mixed emotions associated with the use of the different medical devices and this maps on to the 'offers security and safety' aspect of home in the model described in chapter two. There is little in the literature that has looked at the ability of medical devices to evoke emotional responses and the possible consequences of this. There has, however, been a suggestion that there is a link between negative affect and adherence to medical treatment (Salovey & Birnbaum, 1989), which can be seen as being relevant to medical device usage. The field of assistive devices has looked at this issue and reports that the emotional responses to using these particular types of devices may be a potent factor in their adoption or abandonment (Hocking, 1999).

One aspect of the emotional connection that people have with their home can be seen in terms of the home as a place of safety and security, offering both physical and emotional security (Dahlin-Ivanoff et al*.,* 2007; Despres, 1991). In this way home should be "a womb-like place of security, warmth and comfort,

where it is possible to close the doors and be secure" (Heywood, 2005 p537). It could be suggested, therefore, that medical devices that are not sympathetic to this aspect of the home run the risk of doing emotional harm. This is supported by the anxiety and fear that was expressed by the participants in this study when medical devices were introduced in to the home environment. Rather than closing the front door and feeling safe, they were faced with having to share the house with devices which threatened their emotional security.

Conversely, other participants expressed how having the medical device removed the insecurities and fears brought about by their illness and provided participants with peace of mind and confidence. This could only be achieved by participants having trust in their devices.

While trust in technologies from other domains, for example computer systems, has been extensively studied, this is distinct from trust in medical technologies (Montague et al., 2009). The sense of trust that people have in medical devices is not necessarily a result purely of a characteristic of the device but is a complex social interaction between the technology, people and organisations responsible for issuing the technology (Timmons et al., 2008).

The theme *the accommodating home* describes the impact the physical presence of the device has on 'the physical environment' aspect of home in the working model. This theme describes how devices are assimilated into the environment and how in some cases the home has to be altered to allow its acceptance. The problems faced by participants in this study regarding how aspects of the devices such as noise and aesthetics affected how they fitted in to the environment echoed those found in previous studies looking at medical technology at home (Lehoux, 2004; Fex et al,. 2009).

With the exception of some of the smaller devices in this study (e.g. TENS machines and blood glucose monitors) concessions had to be made with regards to how and where the devices were stored or used. Some devices required alterations to be made to the structure of the home and this was a particularly difficult transition for people who had lived in the same house for many years

and was met with a degree of resistance. When major alterations had to be made to accommodate the devices and associated equipment the responsibility to do so lay with the user or user's partner. In one case, a whole room had to be adjusted to accommodate respiratory equipment.

Five elements or aspects of the physical dimension of the home have previously been identified: structure, materials and finishes; facilities and services; ambient conditions; space and the location of the home (Aplin et al, 2013; Despres, 1991; Oswald & Wahl 2005). In relation to this, the medical devices in this study can be seen to exert an adverse effect on the physical home. Space inside the home has to be found to accommodate the device itself while the noise produced by the oxygen concentrator was seen as interfering with the ambient conditions. The fact that installing some of the larger devices required physical alterations, such as putting up storage shelves, can be seen as affecting the integrity of the home in terms of the structure and finishing of the physical environment.

The use and storage of medical devices in the bedrooms of many of the participants is interesting. While one woman in this study spoke about the intimacy and privacy around using a device it seems that the bedroom may also be a place that devices can be kept away from public gaze (Oudshoorn, 2012). While none of the participants openly spoke of keeping their devices out of sight or any feelings of embarrassment with people seeing the devices in the home it could still have been an unconscious choice to locate the device in a private area of the house. This points to the importance of the human need for dignity and for time away from others especially during times of ill-health (Dyck et al., 2005).

It is generally accepted that being a hospital inpatient entails having to endure a certain loss of privacy in the interests of the level of care provided. Home on the other hand is meant to be the very antithesis of an institution. As with security, loss of privacy at home goes against the very meaning of this, adding to the medicalisation and institutionalisation of the home environment. So while participants with smaller devices may have taken them into private areas within

the home, larger devices would have to be used in-situ which may impact participants' privacy.

The social device theme describes how the device impacted on the lives of device users' partners and wider social circle. This is related to the 'a place to foster relationships' aspect of home in the working model.

When considering the people connected to an individual with a medical condition, the literature has tended to focus on the role of 'family caregiver', i.e. an individual who lives with or close to the ill person and who provides unpaid assistance with prescribed medical care (Winkler et al., 2006). Studies that have looked at spousal carers of individuals suffering from chronic diseases have noted the impact of role change as a mutual, reciprocal relationship that undergoes a metamorphosis into that of a more unilateral, dependant one, where the role of husband/wife is eroded and absorbed into that of carer (Aneshensel et al., 1993). In such cases spousal caring may involve setting up and using a medical device (Lathan et al., 1999).

This change in relationship was not observed in this study which may have been due to the nature of the illnesses and the devices involved; the users in this study required very little in the way of assistance and the role of husband/wife appeared to have remained intact. This meant that the relationship between the spouse and the device was different to the relationship between the device and the user. In this study the spouse and user shared the same physical environment and therefore the spouse was affected by the noise and aesthetics of the device while not directly benefiting from device use (any benefits from the device for the spouse would be deemed as being indirect). The fact that some of these devices were used in a shared bedroom meant that sleep was disturbed or sleeping arrangements had to be altered (changing sides of the bed, sleeping in another room).

There were also emotional consequences of device use on partners. One user reported that the very act of using the device in front of her husband caused the husband to become annoyed. While this may have been an expression of

concern for his wife's health it could also be that it had a detrimental effect on his own identity. A large body of research has shown that being reminded of one's own mortality can be inherently anxiety-provoking and lead to the adoption of defensive emotional responses, for example, avoidance or anger (Marti-Garcia, 2015). Steele et al. (2002) proposed that situational cues that identify a person as belonging to different social group to the one they consider themselves belonging to can lead to social identity threat. In this case conspicuous medical device use may have caused discomfort to this individual as it reminded him of his own age and mortality. The influence on spousal identity has also been discussed in relation to assistive devices used by people who had suffered a stroke and this study reported similar findings (Pettersson et al., 2005).

The effect of device use on others was not entirely negative. One example of the positive effects on others was the benefit they received from the shared use of medical devices with regards to symptom relief or physical function. In two cases, the use of devices was not hidden away from grandchildren but actually became a part of the social interaction with the grandchildren 'helping' with the equipment or 'using' it as part of supervised play. While much has been written about how families experience chronic illness (see Knafl & Gilliss, 2002 for a review of the literature) little has specifically studied the effect of medical devices on the relationship between grandparent and grandchild. The ways that devices were being used in play may be an example of normalisation strategies, which can be used to decrease disruption and maintain family processes (Deatrick et al., 1999).

Home is a place where relationships with family, friends and neighbours can flourish. As a place where relationships with significant others are strengthened and intense emotional connections occur (Despres, 1991; Hayward, 1977), it is the *"presence of and relationships with other people which contribute towards the feeling of home"* (Sixsmith, 1986, p. 291). This theme has illustrated how medical devices can both foster and threaten this aspect of home.

4.5 Limitations

The use of opportunity sampling may have limited the diversity of participants and consequently the generalisability of the findings. Anecdotally, many of the participants in this study reported that they had replied to the adverts out of a sense of 'gratitude' and wanting to give something back which may have biased the interviews. Gratitude bias can be seen, particularly in public funded services such as the National Health Service, where participants are reluctant to criticise and have a tendency to gloss over any negative aspects of services and treatments as they feel they should be grateful for what they receive (Øvretveit, 1992). Linked to this is the suggestion that altruism is one of the main general motivations for people to take part in research (Peel et al., 2006). For example, Warburton and Dyer (2004) found that participants in their study which examined why older people volunteered for a research registry said that they were motivated to volunteer because they wished to make a contribution to society.

While it was not initially the intention to include partners in this study their contribution has been valuable; however, interviewing the user and partner together may have resulted in a less open and frank discussion. The older people in this study seemed less willing to talk about their feelings towards their medical devices than was expected. This may have been due to a reluctance to disclose certain sensitive information. Pre-existing groups, such as couples, can be used to overcoming issues relating to disclosure of a potentially sensitive nature which people may find uncomfortable in stranger groups. Conversely there may be situations where disclosure may be more comfortable in front of strangers (Freeman, 2006). In the case of this study, it might have been difficult for a user's partner to express negative experiences and emotions of having the technology in the home in front of the user, who may be medically dependent on the device.

As this was an exploratory study, participants were primarily drawn from one geographical area in the United Kingdom and, for reasons previously discussed,

one particular age demographic and as such the results should therefore be viewed in the context of the study and the nature of the participants.

While the use of thematic analysis allows for a rich description across the data set, the nuances contained in individual accounts can be lost, thus limiting the complexity and the reporting of individual aspects of the situation from within the data. In this case thematic analysis was used to provide a broad description of the interview content as opposed to making any high order theoretical claims.

4.6 Summary and contribution of this research

This study has identified and described some of the challenges faced by users and their partners in relation to medical device use in the home. The different aspects or characteristics of home that were outlined in chapter two can be categorised into three different modes of everyday home experience: the physical home, the social home, and the personal home. The physical home involves household facilities, architecture, and living accommodations. The social home consists of relationships with others within a shared space and the personal home describes the psychological or emotional connections with the home (Sixsmith, 1986; Oswald & Wahl, 2005).

As discussed in chapter 2, previous research concerning the use of medical devices has mainly focused on safety and usability (e.g. Kaufman et al., 2003; Rajkomar et al. 2015). There has, until now, been no attention paid to how these medical devices foster or threaten different aspects of the home environment. There is a body of literature reviewed in chapter two that has considered the impact of home modifications, undertaken in order to encourage independence and make activities of daily living easier for those physically impaired by accident or illness, in relation to the effect on the different aspects of home (Heywood, 2005; Tanner et al., 2008; Aplin, 2013). However, home modifications instigated by occupational therapists tend to be big adaptations that alter the physical structure of the home, for example, through floor lifts, ramps and rails. Home medical devices, by contrast, do not tend to affect the fabric of the building and

so their influence on the home environment may have been underestimated. The results of this study has built on the previous research undertaken in the home modification field and has shown ways that medical devices can influence the physical, personal and social aspects of the home environment. The themes *striving to maintain control* and *evoking different emotions* demonstrate the effect medical devices have on the personal aspects of home. The theme *the accommodating home* illustrates the influence medical devices have on the experience of the physical home and the theme *the social device* describes how the social home is affected by device use.

4.6.1 Implications of this study for subsequent phases of this research

The findings of this study in conjunction with the literature review have implications for subsequent studies in this thesis:

1. The impact of medical devices on the home environment identified in this first study seems to be analogous with those highlighted in the home modification literature described in chapter two. While home modifications are generally provided by a single healthcare profession (occupational therapists), home medical devices may be provided by different healthcare practitioners from different professional traditions and cultures. This raises the question: in what way, if any, do these different professions consider the home environment when prescribing or providing medical devices? This will be addressed in chapter five, which sets out to answer the question, *what do different groups of healthcare professions consider important in relation to home medical devices?*

2. It is clear from this first study and the literature reviewed in chapter two that medical devices are intrusive and that users are required to make adjustments to the way that they live in their own homes. What is not known, however, is whether the issues raised are stable or are likely to

change over time. This will be addressed in the study described in chapter six, which answers the question, *what is the lived experience of couples who are given a medical device to use at home and how does this change over time?*

Chapter 5: What do different groups of healthcare professions consider important in relation to home medical devices?

5.1 Introduction

The study presented in chapter four identified and described challenges faced by users and their partners in relation to medical devices used in the home and their effect on the physical, social and personal experience of the home environment. This chapter presents the results of an online questionnaire study that aimed to investigate the attitudes and priorities of healthcare professionals about home medical devices.

While medical devices can be bought over the counter or via the internet the most usual way for people with chronic conditions to acquire a medical device is via a healthcare professional (MHRA, 2012). Healthcare is a complex system that comprises different groups of professionals working in different parts of the system such as primary care (e.g. general practitioner or community nursing) and secondary care (e.g. hospital or clinic based staff). To date, no research has been conducted on the processes of providing or prescribing a medical device to patient for use at home. It is not known whether healthcare professionals consider the home environment when providing medical devices and whether this influences their practice. It is also not known whether the various groups of healthcare professionals vary in their attitudes towards home medical devices. This study aims to investigate these questions.

Given doctors and nurses in primary care may be involved in home visits (Leibowitz et al., 2003; Chow et al., 2008), it may be reasonable to suggest that these groups would be more likely to consider the home environment as an important factor when selecting a medical device for an individual than hospital-based, secondary care practitioners. Patients themselves will also have views on

which device is right for them and may not necessarily consider the same factors as important as those considered by healthcare organisations or practitioners.

It is hypothesised, therefore, that professional and non-professional groups will differ in their views on the importance of different characteristics associated with medical devices to be used in the home. In particular, it is suggested that there could be a difference between the hospital-based and community-based practitioners.

5.2 Method

As described in Chapter 3, a quantitative questionnaire approach was considered the most appropriate strategy to address the objective of this study.

5.2.1 Questionnaire development

The questionnaire consisted of two sections; the first section used a paired comparison technique while the second section consisted of open questions.

5.2.1.1 Development of the paired comparison section

The aim of the paired comparison section was to investigate the relative importance of different medical device factors or characteristics to the groups of people involved with their provision and use.

The first step was to identify a comprehensive list of factors relevant to the provision and use of home medical devices. Gupta's (2007) work was used as the basis of this, which used questionnaires and interviews with medical device stakeholders and a systematic statistical analysis to identify 25 different issues that related to the manufacture, design, provision and use of home use medical devices. The results of Gupta's work were then combined with other factors that emerged from literature review and the results of the study presented in chapter four. Nine factors were then selected that were deemed relevant to the participant groups that were to be recruited. The relevance of these factors to home use medical devices was confirmed through discussions with a selection of

healthcare professionals and medical device users. The final list of nine factors or characteristics is described in figure 5.1.

Characteristic	Justification and reference
The instructions are sufficient to enable correct use	**European Union (2012)** Union Commission Regulation (EU) No 207/2012 on electronic instructions for use of medical devices **European Union (1993)** Eu directive -CIL DIRECTIVE 93/42/EEC concerning medical devices **Global Harmonization Task Force (2011)** Label and Instructions for Use for Medical Devices **Gupta (2007)** Design and delivery of medical devices for home use: Drivers and challenges
The device has been tested by real users	**British Standards institution (2008)** BS EN 62366:2008: Application of usability engineering to medical devices. **National Patient Safety Association (2010)** Design for patient safety: user testing in the development of medical devices **Food and Drug Administration (2011)** Applying Human Factors and Usability Engineering to Optimize Medical Device Design **Gupta (2007)** Design and delivery of medical devices for home use: Drivers and challenges
Users receive training prior to use	**MHRA (2014)** Managing Medical Devices: Guidance for healthcare and social services organisations **The Department of Health, Social Services and Public Safety (2008)** Medical Devices And Equipment Management **Study 1:** A qualitative study to describe the impact of home medical device use on the lives of older people.
The device is cost effective	**Ventola (2008)** Challenges in Evaluating and Standardizing Medical Devices in Health Care Facilities **NICE (2013)** Guide to the methods of technology appraisal **Gupta (2007)** Design and delivery of medical devices for home use: Drivers and challenges
The device has undergone clinical trials	**MHRA (2013a)** Clinical investigations of medical devices – guidance for manufacturers **NRES (2008)** Approval for medical devices research **Gupta (2007)** Design and delivery of medical devices for home use: Drivers and challenges
The device reduces clinic/GP appointments	**NHS Choices (2012)** Telecare and telehealth technology **Freedberg, & Feldman (2014)** Remote Monitoring of Patients with Implantable Cardioverter Defibrillators (ICD) . . . **Study 1:** A qualitative study to describe the impact of home medical device use on the lives of older people.
The device has little impact on the home environment	**Fex, Ek & Söderhamn (2009)** Self-care among persons using advanced medical technology at home **Study 1:** A qualitative study to describe the impact of home medical device use on the lives of older people **Gupta (2007)** Design and delivery of medical devices for home use: Drivers and challenges
The outward appearance of the device	**Bitterman (2011)** Design of medical devices--A home perspective **Lang, Martin, Sharples, & Crowe (2013)** The effect of design on the usability and real world effectiveness of medical devices . . . **Study 1:** A qualitative study to describe the impact of home medical device use on the lives of older people.
The patient is offered a choice between different models of the same type of device	**Department of Health (2012)** Government response to the consultation 'Liberating the NHS: No decision about me, without me' **Entwistle, Sheldon, Sowden & Watt (1998)** Evidence-Informed Patient Choice: Practical Issues of Involving Patients in Decisions About Health Care Technologies **Study 1:** A qualitative study to describe the impact of home medical device use on the lives of older people.

Figure 5.1 justifications for device characteristic inclusion

It is worth noting that 'device safety' was not included in the questionnaire as, as discussed in the literature review, safety is the fundamental requirement of any medical device. As a consequence of this, it was predicted that the majority if not all of the participants in each group would consider safety to be the single most important factor associated with a medical device and this therefore would be likely to mask the other factors that are the focus of this thesis.

Similarly, other factors identified by Gupta (2007) as important to design and point of provision such as 'upgradability', 'packaging' and 'shelf-life' were not included as these were not mentioned by any participants in study one.

The initial plan for this part of the questionnaire was to use a Likert-type scale to assess attitude (in terms of importance) towards the different medical device characteristics, with the scale anchored at each end by 'not important' and 'very important'. This initial version was piloted with a doctor and a nurse and advice was also sought from experts in the development of questionnaires. It was found that this questionnaire may be susceptible to response bias, specifically 'social desirability bias'.

Nederhof (1985 p269) describes social desirability bias as a respondent's tendency to "deny socially undesirable traits and to claim socially desirable ones and the tendency to say things that place the speaker in a favourable light". In the case of this questionnaire it was thought that this may lead to healthcare professionals rating all factors as 'very important', which would call in to question the validity of the survey. However, Nederhof (1985) goes on to suggest that 'forced choice' type questions, where respondents are required to make a choice between two different factors, are a way of reducing the effect of social desirability bias. Based on these suggestions the questionnaire was revised and a 'paired comparisons' technique used to allow ranking of the relative importance of the different medical device characteristics or factors. This forced choice approach is particularly appropriate for the healthcare environment where there are usually many competing priorities. The importance and difficulty of considering and meeting these different needs has been identified in previous

work on the design and development process of medical devices (Martin et al., 2008). The forced choice approach also forms part of the Analytic Hierarchy Process which has been used in health technology assessment and user needs elicitation (Pecchia et al., 2013).

The paired comparisons technique was popularised by Thurstone (1927a; 1927b). The method allows participants to judge a set of items by presenting all possible pairs of the items to each individual who then selects the item in each pair that best satisfies the selection criterion (e.g. more important, more difficult) without being offered a 'neutral' or 'indifferent option' (Brown & Peterson, 2009). The number of items to be judged, however, can quickly become prohibitive and laborious for participants as the number of pairs presented increases (McKenna et al., 1981). Where t = the number of items, there are t(t – 1)/2 pairs in total. In this study, the nine items to be compared resulted in 36 presented pairs.

When respondents are offered a list or set of answers there may be a risk of ordinal biases where people have a tendency to choose options at either the beginning or end of the list (Krosnick, 1999). Even when only two possible options are given, as with this questionnaire, there is a tendency to choose the latter option. In order to lessen the effects of this type of bias and that of response fatigue, where long questionnaires may induce fatigue which may result in uniform and inaccurate answers, both the order of the questions and the order in which the pairs of items were presented were randomized for each participant (Oppenheim, 1992; Choi, & Pak, 2005).

5.2.2.2 Development of the open question section

The second section of the questionnaire consisted of open free text questions. Open-ended questions are useful for explaining and clarifying quantitative findings (Jackson & Trochim, 2002). While any number of open questions could have been included, the potential of participant fatigue with an overly long questionnaire was a concern and therefore the questions were limited to five for the professionals and three to the non-professionals.

The open-ended questions were developed based on the results of first study. The theme *striving to maintain control* (see section 4.4 in Chapter four), described how having limited choice over the particular type or make of device that participants were given undermined people's ability to choose or control different aspects of their home life and previous research has described how this can be damaging to physical and mental health (Langer & Rodin, 1976; Shultz, 1976). Given the current drive for greater patient-centred care and empowered and informed patients noted in chapter two, it was decided that the open questions should focus on exploring these issues further.

The open questions were tailored to the participant group: healthcare professionals were presented with five open questions, medical device users aged 65 or over were presented with three open questions and non-medical device users aged 65 or over were presented with three different questions.

Three versions of the questionnaire were developed using Surveygizmo® online survey software: one version for healthcare professionals and one for device users and one for non-device users. The differences included were due to a need for slightly different wording about incentives, asking for professional/personal opinions and the open questions (see appendix two for the full medical device user questionnaire).

5.2.3 Participants

Following approval from the University of Nottingham faculty of engineering ethics committee, seven groups of participants were recruited. The groups comprised: hospital doctors, hospital nurses, general practitioners (GPs), community nurses, hospital pharmacists, medical devices users aged 65 or over and non-medical device users aged 65 or over (see table 5.1). These groups were chosen as they represented the healthcare professionals from both primary and secondary care that are directly involved in the provision of medical devices to be used at home. Users and non-users of medical devices were included in order

to capture any differences in what these groups consider important in home medical devices.

For reasons previously discussed (chapter three section 3.3.1.3) and to ensure continuity between studies, medical device users and non-users included in this study were again selected from the 65 and over age group.

	Mean age	Gender
Hospital doctor	47.7	Male 38
		Female 12
GPs	48	Male 30
		Female 20
Hospital nurse	47.7	Male 8
		Female 42
Community nurse	49.2	Male 8
		Female 40
		Prefer not to answer 2
Hospital pharmacist	38.1	Male 21
		Female 29
Medical device user	69.3	Male 22
		Female 28
Medical device non-user	70.5	Male 22
		Female 28

Table 5.1 Study 2 participant demographics

The healthcare professionals were recruited via an online research panel (Research Now™) in line with the study ethics approval. Online panels are an important and growing method of web based data collection. Panels can be defined as a pool of people who have registered and agreed to take part in online studies on a regular basis and are particularly useful in accessing specialist or hard to reach groups and increasing response rates (Goritz, 2004). Possible disadvantages of using this type of panel are: recruitment bias (where the sample selected is skewed in a particular way) and conditioning bias (where repeated participation in research projects biases responses to later questions or interviews) (Nancarrow & Cartwright, 2007). While these disadvantages are

acknowledged, it was felt that the difficulty of accessing these particular groups of participants outweighed the possible biases. While there may have been other professional groups involved in the provision of medical devices (i.e. physiotherapists), the expense involved in using a research panel for recruitment meant that inclusion of other practitioner groups was not economically viable and so can be seen as another disadvantage of this recruitment strategy.

The healthcare professionals were randomly sampled from the specialist healthcare panel compiled by Research Now™ and provided with the web address from which to access the questionnaire. Panel respondents who completed the questionnaire received a small remuneration for their participation.

Participants falling into the users/non-users of medical devices group were recruited via emails to charities, older peoples groups and snowball sampling of personal contacts. For every respondent from these groups who completed the questionnaire a donation of £1 was made to charity (The British Lung Foundation).

An *a priori* computation of required sample size was conducted using G*Power 3 (Faul et al., 2007). It was determined that with an effect size f =0.25 (Cohen, 1998 suggests that f values of 0.25 represent a medium effect sizes), power (1-β err prob) =0.95 and number of groups =7, the total sample size needs to be 343 participants (49.29 per group). Fifty participants were recruited for each group and all participants were from the UK.

5.2.4 Procedure

On accessing the questionnaire, participants were presented with a welcome page which explained the purpose of the questionnaire and gave assurances regarding confidentiality, the right to withdraw and data protection. The second page asked for some demographic information. The third page asked respondents to think about a particular type of medical device that is used in the home. This was required because it was felt that due to the wide variety of

medical devices it may have been difficult for participants to complete the questionnaire if they were thinking about all possible devices. For example, participants may have found it confusing when considering characteristics that may be extremely important for one medical device but not for another. The following section contained further instructions and the pairings from which the most important was to be selected. The open questions were presented in the next section and the final page was a thank you page with contact details and a link for further information. The questionnaire was designed so that participants were unable to progress to the next section unless all the questions had been answered.

5.2.5 Statistical analysis

The paired comparison method was used to rank in the factors or characteristics considered most important by the different respondent groups (David, 1988). For each pair that was presented to respondents (e.g. *The device has been tested by real users*-vs- *Instructions are sufficient to enable correct use*) a score was calculated based on how many times each characteristic was chosen as being more important that the other. For example, from the 50 hospital doctors sampled 30 selected '*The device has been tested by real users'* and 20 selected '*Instructions are sufficient to enable correct use'*. These scores were then used to create a 9 by 9 matrix where the columns represent the score for the characteristic. The next step involved converting these scores into a probability of each item being selected (e.g. in the column for '*The device has been tested by real users'* compared to '*Instructions are sufficient to enable correct use'*, the probability of the former being selected was 0.60. The same attributes compared to one another was 0.50.

The next step was to use the property of the normal distribution curve to convert these probabilities to z-values or scores. A z-score is a statistical way of standardizing data on one scale so a comparison can take place. This is best illustrated by reference to Fig. 5.2, which shows the 60 per cent point on a normal curve, i.e. the point on the curve where 60 per cent of the distribution

falls to the left. If the mean of the curve is set to zero and the standard deviation to 1, this occurs at a value of -0.25. As a result, the probability value of 0.40 is replaced by a z-value of −0.25.

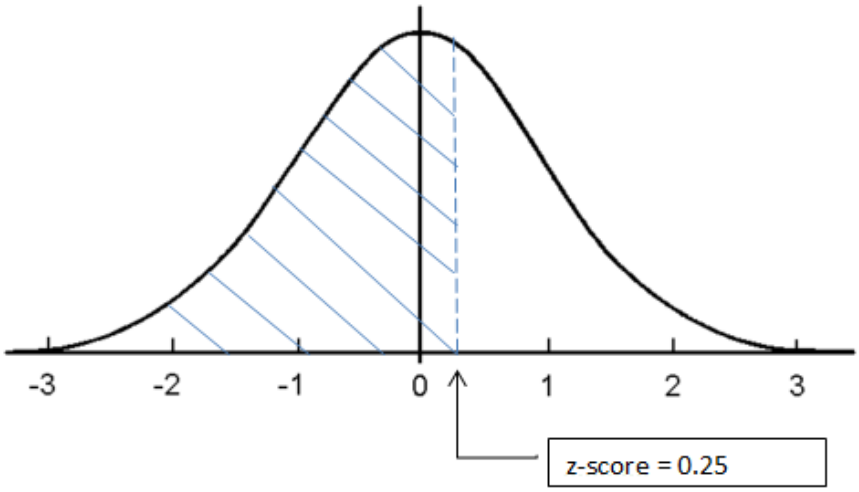

Figure 5.2 Normal distribution curve

The z-scores for each column were then summed and the mean calculated. This provided the z-score equivalent to the mean probability of each item being selected over all other items. The range of negative and positive numbers can be distracting, so a constant (+3) was added to all the values to avoid negative weights and so aid clarity. These weights can be assumed to have interval properties i.e. numerically equal distances on the scale reflect equal differences in the underlying dimension thus facilitating meaningful comparisons between scores (see appendix 3 for example. Also see Streiner and Norman (2008) and Conlon et al. (2012) for other worked examples). This process was repeated for each of the seven respondent groups.

The appropriate statistical tests (Kruskal-Wallis H tests and Mann-Whitney post hoc tests) were carried out using IBM SPSS Statistics 20 (IBM Corp., 2011) to determine if there were between group differences (i.e. between hospital doctors and community nurses) on the scores of the various device characteristics. In order for statistical analysis to be carried out scores from the

pairwise comparisons (either 1 or 0) for each characteristic were added together. This created a total score for each characteristic for each individual respondent for which the maximum score that could be achieved for each characteristic was 8 which was then entered into the SPSS database for analysis.

5.2.6 Qualitative analysis

Qualitative data from the open ended questions were analysed using NVivo 9 software (QSR international Pty Ltd., 2010). The responses given to these questions were organised into themes based on Braun and Clarke's (2006) method of thematic analysis that has been described in study one. Open ended survey responses can be particularly challenging to analyse, often comprising of a series of bullet point type lists or very concise narratives. They may also include responses that are made up of a number of paragraphs that contain a variety of concepts. It is for these reasons that a "quantitative translation" (Boyatzis, 1989) was applied in which the qualitative themes are numerically expressed in order to describe the findings.

This process consisted of five stages carried out separately for each open question:

Stage 1: started with engagement with and familiarisation of the data where participants' answers to each question were entered into NVivo 9, read and reviewed.

Stage 2: involved the systematic generation of initial codes from the data.

Stage3: refocused the analysis at a broader level of combining and sorting these codes to produce potential themes.

Stage 4: the preliminary set of themes were then revisited and refined to produce a set of themes that were distinct and meaningful.

Stage 5: the total number of references to each theme was calculated for each participant group.

The use of numerical/quantitative data in qualitative research studies is controversial as a result of fundamentally different approaches to generating new knowledge influenced by the two major paradigms – positivism and interpretivism (Maxwell, 2010) as discussed in chapter two. Becker (1970) has challenged this, arguing that qualitative researchers often make quantitative claims in verbal form, using terms such as: *many, often, typically, sometimes*, etc. He claims that numbers support these terms and make such claims more precise. A similar point is made by Sandelowski et al. (2009) in that "quantitizing" qualitative data is done in qualitative research "to facilitate pattern recognition or otherwise to extract meaning from qualitative data, account for all data, document analytic moves, and verify interpretations" (p. 210) and is common in mixed methods research.

A problem with converting qualitative data into numbers is that the numbers can lead the researcher or reader to infer greater generality for the conclusions than is justified, by neglecting to take account of the specific context within which the data is collected. There is also a danger that interpretations about causes, consequences, and relationships can be made in relation to the assumptions of qualitative analysis converted in to numerical data and begin to be thought of in terms of correlational designs, quantitative measurement, and statistical analysis (Maxwell, 2010).

However, the qualitative data in this study will be numerically expressed to aid identification of patterns that are not apparent simply from the unquantitized qualitative data.

5.3 Results and discussion

For the purpose of clarity, the results and discussion of the paired comparisons and open question sections will be presented separately.

5.3.1 Results from the paired comparison rank order of attributes

Overall and group mean weighted z- scores are presented in table 5.2. Overall scores were included to show the ranking of characteristics as a whole. There was more variability between characteristic rankings by the different respondent groups in the top five positions than those characteristics positioned in the bottom four positions.

The paired comparisons method provides important information regarding the rank order of device attributes or factors associated with device provision between the different respondent groups. It was also important to determine whether there were between group differences in the weightings of specific attributes or factors. Significant differences and effect sizes were calculated for between group differences in characteristic importance.

As the data were found to be not normally distributed, Kruskal-Wallis H tests were conducted to evaluate differences among the participant groups in relation to the relative importance of different device characteristics. The results showed that there was no significant difference between the groups in relation to the following characteristics:

The device has been tested by real users $\chi^2(6) = 5.985$, $p > 0.05$

The instructions are sufficient to enable correct use $\chi^2(6) = 9.751$, $p > 0.05$

The device has undergone clinical trials $\chi^2(6) = 7.160$, $p > 0.05$

The device reduces clinic/GP appointments $\chi^2(6) = 9.782$, $p > 0.05$

The outward appearance of the device $\chi^2(6) = 6.378$, $p > 0.05$

The patient is offered a choice between different models of the same type of device $\chi^2(6) = 10.414$, $p > 0.05$

Rank \ Group	Overall (n=350)	Hospital Doctor (n=50)	General practitioner (n=50)	Hospital nurse (n=50)	Community nurse (n=50)	Hospital pharmacist (n=50)	Over 65's non user (n=50)	Over 65's medical device user (n=50)
1	Users receive training prior to use (3.72)	The device has been tested by real users (3.51)	Users receive training prior to use (3.58)	Users receive training prior to use (3.88)	Users receive training prior to use (3.77)	The device has been tested by real users (4.03)	Users receive training prior to use (3.85)	Instructions are sufficient to enable correct use (3.76)
2	Instructions are sufficient to enable correct use (3.68)	The device has undergone clinical trials (3.50)	The device reduces clinic/GP appointments (3.51)	The device has undergone clinical trials (3.66)	Instructions are sufficient to enable correct use (3.71)	Users receive training prior to use (3.77)	Instructions are sufficient to enable correct use (3.82)	The device has been tested by real users (3.60)
3	The device has been tested by real users (3.55)	Instructions are sufficient to enable correct use (3.43)	Instructions are sufficient to enable correct use (3.47)	Instructions are sufficient to enable correct use (3.51)	The device has undergone clinical trials (3.60)	Instructions are sufficient to enable correct use (3.67)	The device has been tested by real users (3.71)	Users receive training prior to use (3.54)
4	The device has undergone clinical trials (3.55)	Users receive training prior to use (3.41)	The device has been tested by real users (3.45)	The device has been tested by real users (3.45)	The device has been tested by real users (3.44)	The device has undergone clinical trials (3.25)	The device has undergone clinical trials (3.66)	The device has undergone clinical trials (3.54)
5	The device reduces clinic/GP appointments (3.27)	The device is cost effective (3.29)	The device has undergone clinical trials (3.43)	The device reduces clinic/GP appointments (3.22)	The device reduces clinic/GP appointments (3.18)	The device reduces clinic/GP appointments (3.19)	The device reduces clinic/GP appointments (3.24)	The device reduces clinic/GP appointments (3.37)
6	The device is cost effective (2.94)	The device reduces clinic/GP appointments (3.25)	The device is cost effective (3.39)	The device is cost effective (2.81)	The device is cost effective (3.05)	The device is cost effective (3.12)	The device has little impact on the home environment (2.74)	The patient is offered a choice between..... (2.65)
7	The device has little impact on the home environment (2.37)	The device has little impact on the home environment (2.67)	The device has little impact on the home environment (2.47)	The patient is offered a choice between..... (2.52)	The device has little impact on the home environment (2.53)	The device has little impact on the home environment (2.37)	The device is cost effective (2.37)	The device is cost effective (2.62)
8	The patient is offered a choice between...(2.36)	The patient is offered a choice between...(2.35)	The patient is offered a choice between...(2.25)	The device has little impact on the home environment (2.43)	The patient is offered a choice between...(2.07)	The patient is offered a choice between...(2.34)	The patient is offered a choice between...(2.36)	The device has little impact on the home environment (2.42)
9	The outward appearance of the device (1.67)	The outward appearance of the device (1.57)	The outward appearance of the device (1.65)	The outward appearance of the device (1.68)	The outward appearance of the device (1.84)	The outward appearance of the device (1.26)	The outward appearance of the device (1.37)	The outward appearance of the device (1.50)

Table 5.2 Overall and group mean weighted *z*-scores (each colour represents a particular device characteristic)

Statistical significant differences were found between the groups for the following characteristics:

Users receive training prior to use $\chi^2(6) = 27.069$, $p < .000$

The device is cost effective $\chi^2(6) = 77.711$, $p < .000$

The device has little impact on the home environment $\chi^2(6) = 18.913$, $p < .005$

Mann-Whitney post hoc tests were used to evaluate pairwise differences between the participant groups and these device characteristics. To control for type I errors across tests (believing that there is a genuine effect when in fact there is not) a Bonferroni correction (dividing the critical P value (0.05) by the number of comparisons being made) was applied. In order that this correction did not become too restrictive, selective comparisons were made (Field, 2005) based on a difference in Kruskal-Wallis mean ranking of ≥ 50 between participant groups. The Kruskal-Wallis test is based on ranked data. SPSS starts by substituting the rank in the overall data set for each measurement value. SPSS calculates the mean rank output which is then used to compare the effect of differences among the participant groups in relation to the relative importance of different device characteristics. A difference in Kruskal-Wallis mean ranking of ≥ 50 between participant groups was chosen as the cut-off as below this threshold the Mann-Whitney post hoc tests did not appear to be significant.

Effect size *r* for the following Mann-Whitney tests was calculated by dividing the resulting *z*-score by the square root of the total sample size on which it is based ($r = \frac{z}{\sqrt{N}}$) as recommended by Field (2005). Widely accepted notions about what constitutes a large or small effect have been suggested by Cohen (1992):

•r = 0.10 (small effect): the effect explains 1% of the total variance.

•r = 0.30 (medium effect): the effect accounts for 9% of the total variance.

•r = 0.50 (large effect): the effect accounts for 25% of the variance.

5.3.1.1 Differences between participant groups in relation to the importance of 'users receive training prior to use'

Mann-Whitney tests indicated that in terms of the importance of the device characteristic '*users receive training prior to use'*:

Hospital nurses reported higher scores than:
Hospital doctors (U = 172.5, Z = -3.77, p< .001, r = -0.38),
GPs (U = 834.0, Z = -2.93, p= .003, r = -0.29) and
Device users (U = 823.5, Z = -3.01, p= .003, r = -0.30).

Hospital pharmacists reported higher scores than:
Hospital doctors (U = 754.5, Z = -3.47, p= .001, r = -0.35).

Non device users reported higher scores than:
Hospital doctors (U = 856.0, Z = -2.76, p< .006, r = -0.28)

Community nurses reported higher scores than:
Hospital doctors (U = 839.5, Z = -2.88, p< .004, r = -0.29).

All effects are reported at a 0.006 level of significance.

5.3.1.2 Differences between participant groups in relation to the importance of 'the device is cost effective'

Mann-Whitney tests indicated that in terms of the importance of the device characteristic *'the device is cost effective'*:

GPs reported higher scores than:
Community nurses (U = 695.0, Z = -3.91, p< .001, r = -0.39),
Hospital nurses (U = 599.5, Z = -4.58, p< .001, r = -0.46),
Device users (U = 459.5, Z = -5.53, p< .001, r = -0.55)
Non-users (U = 374.0, Z = -6.10, p< .001, r = -0.61).

Hospital doctors scored higher than:
Community nurses (U = 808.5, Z = -3.11, p= .002, r = -0.31),
Hospital nurses (U = 707.0, Z = -3.82, p< .001, r = -0.38),
Device users (U = 555.0, Z = -4.86, p< .001, r = -0.49)
Non-users (U = 450.5, Z = -5.56, p< .001, r = -0.56).

Hospital pharmacists scored higher than:
Device users (U = 713.5, Z = -3.75, p< .001, r = -0.38)
Non-users (U = 726.5, Z = -3.70, p< .001, r = -0.37).

Community nurses scored higher than:
Non-users (U = 717.5, Z = -3.73, p< .001, r = -0.37).

Hospital nurses scored higher than:
Non-users (U = 809.0, Z = -3.10, p= .002, r = -0.30).

All effects are reported at a 0.004 level of significance.

5.3.1.3 Differences between participant groups in relation to the importance of 'the device has little impact on the home environment'

Mann-Whitney tests indicated that in terms of the importance of the device characteristic *'the device has little impact on the home environment'*:

Non-users reported higher scores than:
GPs (U = 767.5, Z = -3.43, p= .001, r = -0.34),
Hospital nurses (U = 790.5, Z = -3.26, p= .001, r = -0.33)
Pharmacists (U = 726.5, Z = -3.70, p< .001, r = -0.37).

All effects are reported at a 0.013 level of significance.

5.3.2 Discussion of the paired comparison rank order of attributes

The objective of this study was to investigate which characteristics or factors associated with medical devices that are used in the home are considered the most important by healthcare professionals and device users and whether there are any differences between these groups.

The results of this study did not support the hypothesis that there would be a difference between the hospital-based and primary care practitioners in terms of the relative importance of factors related to home medical devices. Primary care based healthcare practitioners (GPs and community-based nurses) did not rate the home environment as more important when selecting a medical device for an individual than hospital-based healthcare professionals. In fact all professional groups ranked factors concerning: the home environment, choice and

appearance less important than factors concerning: training, instructions, user testing, clinical trials, reducing appointments and cost effectiveness. A similar pattern was observed in the non-professional groups that only differed in that non-users ranked the home environment higher than cost effectiveness and device users' ranked choice higher than cost effectiveness.

The results indicate two main findings:

- There is little difference between the groups as to the ranking in importance of the different device characteristics.
- There is a split between those characteristics that are generally considered more important and less important that is reported by all groups.

The first finding of this study that the factors which professional groups generally agree are most important is not supported by the qualitative literature or the results from the study presented in chapter four. Professionals in the present study ranked factors concerning the home environment, choice and appearance in the lowest positions whereas qualitative studies have shown these factors to be particularly relevant to device users and their partners. The lack of consideration of these factors by the different professional groups does not chime with a holistic or whole person approach to patient care; this considers the needs of the patient as a whole and broadens the focus of medical treatment to include an understanding of people's lives, environments, values and goals rather than treating only the medical problem (Royal College of General Practitioners, 2014).

The apparent lack of holistic consideration may indicate that in this study, at least as far as medical devices are concerned, a more paternalistic approach as to what is important in selecting a device has been adopted. In general the characteristics toward the top of the rankings seem to be related to the practicalities of device use which is in line with more traditional approach of promoting information and technical skills with a view to promoting compliance with treatments to improve clinical outcomes (Bodenheimer et al., 2002). Age

and the type of medical education and training were found by Bodenheimer et al. to be highly influential with more recently qualified practitioners considered to be more open to patient empowerment and less inclined to be paternalistic than those practitioners that qualified many years ago (Scambler, 2012). This may also be a factor given that the mean ages of doctors and nurses that participated in this study were in the late 40s and therefore they may not be as aware or comfortable with a more holistic, patient centred way of working.

The traditional, paternalistic model of medical decision-making assumes that while doctors and patients share the same goals, it is only the doctor who is sufficiently informed and experienced to decide what should be done, and that the patient's only involvement should be to give or withhold consent to treatment (Coulter & Ellins, 2006). The literature review in chapter two discussed how the Chronic Care Model (CCM) and NHS and Social Care Long Term Conditions Model encourage healthcare practitioners to relinquish paternalistic patient management and instead involve people in their own care. Thus the clinician's role should shift from that of professional expert who instructs and decides to that of a guide who supports and advises.

There is plenty of evidence that many patients want more information than they are currently given (Coulter & Magee 2003), but this does not necessarily mean they want to participate in decision-making. Studies exploring the extent to which patients want to participate in decisions have shown people's preferences may vary according to a number of factors for example: the stage and severity of their condition (Beaver et al., 1999; Davey et al., 2002), age-related trends where younger and better educated people are more likely to want to play an active role in decision making (Krupat et al., 2000; O'Connor et al 2003) while older people are more likely to defer to healthcare professionals for decisions about treatment (Levinson et al., 2005) and cultural differences (Coulter & Magee, 2003). This suggests that it is even more important that healthcare professionals consider all issues, as patients aren't likely to bring them up themselves. As a result it has been concluded that patients should be informed of treatment

alternatives and involved in treatment decisions when more than one effective alternative exists (Guadagnoli & Ward 1998).

This ethos has become entrenched in both political and professional documentation. For example section 3a of the NHS constitution states *"You have the right to be involved in discussions and decisions about your healthcare . . . and to be given information to enable you to do this."*(DoH, 2013 p9) and the General Medical Council (2013b) emphasises that doctors have a duty to work in partnership with patients, providing information to enable the patient to reach a decision about treatment and care and respecting that decision. In essence, this paradigm shift emphasises the importance and value ascribed to choice with regards to healthcare.

The Department of Health's focus on patient choice was set out in the document Equity and Excellence: Liberating the NHS (DoH, 2010a) and is based on evidence that involving patients in their care can improve health outcomes (e.g. Kaplan et al., 1989), improves patient satisfaction with services (Stevenson et al., 2004), improves the management of long-term conditions (Heisler et al., 2002) and can also result in significant cost savings (Wanless, 2002). The aspirations and plans set out in *Equity and Excellence: Liberating the NHS* have been further refined and the current version of the Department of Health's Choice Framework for NHS funded care brings together the choices available to all patients along the care pathway. People can expect to have choices in following areas:

- Choosing your GP practice
- Choosing where to go for your first appointment as an outpatient
- Choosing asking to change hospital if you have to wait longer than the maximum waiting times
- Choosing who carries out a specialist test if you need one
- Choosing maternity services
- Choosing services provided in the community
- Choosing to take part in health research
- Choosing to have a personal health budget

- Choosing to travel to another European country for treatment

For other healthcare services, there is no legal right to choose, but people should be offered choices, depending on what is available locally (DoH, 2014, p 2).

While this at first appears to be quite a comprehensive commitment to patient choice it does not deal with the specifics or details involved in treatments that may become more important to patients especially with patients being seen increasingly as consumers (Ogden et al., 2008).

In spite of policy commitments and evidence of benefit, the evidence suggests that exploration of patients' values and preferences and the promotion of true shared decision-making are not widely practised (Coulter & Ellins 2006; Nuño et al., 2012; Stiggelbout et al., 2015). In order to replace the philosophy of traditional and paternalistic model of healthcare with one that promotes patient choice and shared decision making, adequate support systems within the health setting are required (Asimakopoulou, 2007; Corbally et al, 2007) and that supporting patients in this way requires that healthcare team members have the time, knowledge, and expertise required to develop personalised plans of care (Novak et al., 2013; Tobiano et al., 2015).

While this interpretation of the findings suggests a lack of holistic consideration towards patient care, it is important to remember that the ranking of characteristics are relative i.e. the factors at the top of the table are not necessarily the most important characteristics only that they are considered more important than those lower down in the table. Similarly, those factors at the bottom of the table are not unimportant but only considered less important than those at the top of the table. There may be factors not included in the study that would be considered less or more important than those that were included in the survey. Similarly, factors associated with basic functioning and instruction may be viewed as a prerequisite of the ability to use the device (without which would render the device ineffectual) and therefore would be considered particularly important aspects of a medical device.

The similarities between the rankings of device characteristics between healthcare practitioners and device users/non-users may reflect that people with chronic diseases may have been socialised into the medical model way of thinking that reduces illness to a set of signs and symptoms to which the selection of appropriate therapy is required to improve the patient's condition with little consideration of non-medical aspects of problems (Bodenheimer et al., 2002; Mead & Bower, 2000). This also promotes patients to relinquish control and responsibility for decisions to healthcare professionals especially as age increases (Auerbach, 2001; Thompson et al., 1993).

Alternatively, the similarities between healthcare practitioners and device users/non-users may be interpreted as the latter groups displaying a lack of concern regarding these factors. The findings of this study in relation to the factors which professional groups generally agree are more important are not supported by the qualitative literature or the results from the study presented in chapter four. This may be an indication that the qualitative approach taken may have focused unduly on some of the psychosocial issues, without revealing the extent of people's feelings towards the more practical issues.

While steps were taken, in terms of using a paired comparison study design, to limit the effect of 'social desirability bias', the similarity of responses given by the healthcare practitioners could indicate the influence of socially expected responses.

It is also worth recognising the difficulty in capturing the tacit knowledge (i.e. knowledge that's difficult to write down, visualise or transfer from one person to another) that may have been built up by healthcare practitioners over years of observation, imitation, and practice.

The remainder of this section will examine the second main finding that there is a split between those characteristics that are generally considered more important and less important that is reported by all groups.

It can be seen from the group rankings presented in table 5.2 that there is considerable variation in the rankings of device characteristics in the top part of the table compared to the variation seen in the lower part of the table. This suggests that there are 2 categories: those that are of greatest importance at the top compared with those that are less important at the bottom. It seems that although there is a high level of agreement about what characteristics are of primary and secondary importance, there is little agreement as to the relative importance of the characteristics within these categories. This may in some part be explained by the effect of the responsibilities associated with different occupations.

The characteristic '*users receive training prior to use*' is ranked highly by GPs, pharmacists and both hospital and community nurses, with hospital doctors' scores of this characteristic being significantly lower than that of pharmacists and of both nursing groups. The differences in rankings and attribute scores may be related to professional groups who are responsible for training device users or having to deal with the problems those users face.

GPs provide a complete spectrum of care both in GP surgeries and patients' homes. They require an extensive knowledge of medical conditions that enable them to help patients with regards to disease education, prevention, assessment and treatment (NHS Careers, 2014). This in turn requires the prescription of a wide range of medical devices which they are responsible for ensuring that the patient knows how to use correctly (General Medical Council, 2013a). Similarly, training and education of patients is a major component of the nursing role (Royal College of Nursing, 2003) and may explain why this characteristic is ranked highly by these groups. The proliferation of specialist and advanced nursing practitioners, particularly in hospitals, occurred in part due to an increased demand in services and an expansion in knowledge and expertise, particularly in new medical technologies. This in turn has led to a blurring of traditional professional roles with nurses taking on responsibilities that would have once been thought of as the role of doctors (Hunt, 1999; Daly & Carnwell, 2003). This may help explain why hospital doctors ranked training users as less important.

Hospital doctors may be less involved with this particular aspect of patient care as it has become more associated with that of hospital nursing staff. This characteristic was also ranked highly by hospital pharmacists, which is not that surprising given the nature of their role in patient focused care by supporting disease self-management through advice and education of medication (and where necessary its delivery system) and monitoring equipment (Anderson, 2002). This may also explain why those groups involved in face to face patient training ranked it as more important than the quality of the instructions.

The ranking for the characteristics concerning cost effectiveness and reducing clinic/GP appointments were similarly ranked between the groups, at around positions 5 and 6 with some fluctuations. Their similar rankings highlight the relationship between the two factors in that reducing appointments reduces the cost to the NHS. Both general practitioners and hospital doctors rated device cost effectiveness significantly higher than the other healthcare groups.

The announcement by the Department of Health and Social Security in 1997 emphasised the need for clinicians to be given information about costs of local services in order that they can make informed and appropriate decisions on the best use of resources (Department of Health and Social Security, 1997) However, in a recent study there was little support for the idea that cost played an important role in clinical decisions regarding choice of treatment (unless there were different treatments of similar efficacy then cost would play a role) but there was strong support that cost played an important role when it came to decisions related to medical equipment (Jacobs et al., 2004).

As part of the implementation of the Health and Social Care Act (2012), the previous administration of local healthcare by primary care trusts was abolished with GPs and GP consortia being given the role of commissioning local services to maximise health outcomes, but also to keep within budget restraints. So it can be surmised that the importance of medical devices that are cost effective is reflected in the fact that doctors in hospitals and GPs in the community are

becoming more responsible and accountable for budgets and costs of healthcare.

A notable exception to the ranking position of the characteristic concerned with reducing appointments can be seen with GPs' ranking of this characteristic as the 2nd most important. This may be due to the increased waiting times for GP appointments which are predicted to increase over the next two years (Royal College of General Practitioners, 2013). Increased waiting times are associated with increased non-attendance of appointments (Murray, 2000) which in turn result in increased cost to the NHS. These costs can be in terms of unused or misused personnel time, equipment and capacity or a loss of income where providers of care are reimbursed by a fee-for-service scheme (Bech, 2005) all of which are of increasing importance to GPs with the introduction of GP commissioning (National Association of Primary Care, 2010). As the number of older people living with long-term conditions grows the demand for GP appointment has also increased (The Kings Fund, 2015). Therefore, devices that have even a small impact on this group could result in a big impact on GP appointments, services and waiting times.

The characteristics relating to the home environment, choice and device appearance were predominantly ranked in the final 3 positions by the different groups (although some fluctuation can be seen in the non-medical professionals groups). Non device users did score the characteristic concerned with the home environment as significantly more important than GPs, hospital nurses and pharmacists. The reason for this is not clear but may have something to do with wanting to reduce the disruption of ill-health or rejecting thoughts of permanent change. The fact that this difference was not observed in the device users lends support to this view, as in reality, device users with a long term condition may become less worried about these things and more concerned with feeling better.

The second main finding is that there is a split between those characteristics that are generally considered more important and less important that is reported by all groups. The similarity of ranking and positioning of the bottom three

characteristics concerning choice, appearance and the impact on the home environment, may have less to do with group responsibilities and be more related to the nature of the characteristics themselves. In general the characteristics toward the top of the rankings seem to be related to the practicalities of device use. The characteristics concerning cost effectiveness and reducing clinic/GP appointments in the central positions are more financially focused and the characteristics positioned in the lower part of the table seem to be more related to user satisfaction.

Linder-Pelz (1982) approached a definition of patient satisfaction based on Fishbein and Ajzen's (1974) social-psychological theory of attitudes and beliefs. From this satisfaction is based on the belief that the care/treatment possesses certain attributes (components/dimensions) and that satisfaction is the patient's positive evaluation of those attributes. Underpinning those beliefs and attitudes are a person's expectations about the treatment/event and its outcome, the value of the treatment/encounter and a person's entitlement for seeking that treatment. Patient satisfaction thus becomes defined as "the individual's positive evaluations of distinct dimensions of health care" (Linder-Pelz, 1982, p. 580).

The most commonly favoured model of satisfaction research has been termed the "discrepancy model". Fox and Storms (1981) argued that satisfaction responses displayed a lack of variability and that shifting the focus from obtaining stability of results to attempting to understanding the conditions under which discrepant findings or dissatisfaction can be predicted would be of greater benefit. Williams (1994) argued that patient expectations were the key to understanding the reasons for expressed dis- satisfaction and in doing so acknowledges and connects with the work of Linder-Pelz (1982). The discrepancy model argues that satisfaction is relative, defined by the difference between patients expectations about a treatment or healthcare encounter and their actual experience of that event. Dissatisfaction, however, is only expressed when extreme negative events occur. This means that positive patient satisfaction responses do not necessarily imply 'good' care or treatment but simply that the treatment or care was not extremely bad (Sitzia & Wood, 1997).

If it is the case that characteristics identified in the present study concerning choice, appearance and the impact on the home environment are more associated with patient satisfaction then it may be possible that these characteristics only become important in the presence of extreme negative events. For example the appearance of a device or impact on the home environment may only become important if the device is too large or noisy for the room in which it is situated. The effect of choice on dissatisfaction may be activated when patients know that there is a choice that they could be offered but is not presented to them.

The literature suggests that when asked about issues concerning health and social care in general there are many reasons why people may be more likely to overstate their satisfaction (Calnan, 2003; Canlan et al., 2003). It may also be the case that the same is true when patients are asked about their medical devices. Their exposure to health services may have lowered expectations and that just being given a device to use is totally acceptable. This may explain why in this study if users are in general more satisfied with their healthcare and devices then 'satisfier' factors may be deemed less important that if they were dissatisfied. However, this does not explain some of the results from the qualitative literature.

Qualitative research that focuses on the experience of people who use medical devices (see Lathan et al., 1999; Lehoux et al., 2004; Ingadottir & Jonsdottir, 2006; Fex et al., 2009) rarely mentions the characteristics or factors that have been ranked highly in terms of importance in this study This may imply that because they are of such importance great time and effort has been invested into addressing any issues associated with these factors either by legislation, standards or government strategy. However, results of qualitative research that focuses on the experience of people who use medical devices often centres on issues associated with factors ranked of low importance in this study. It could be argued then that if these factors were considered equally important as the higher ranked factors and greater time and effort given to addressing those issues, people may qualitatively report less issues related to those factors.

5.3.3 Results from the questionnaire open questions

The results from the open questions are displayed in the following figures for each question with the corresponding themed answers and number of references for each theme for each participant group. All 50 participants in each healthcare professional group completed the open questions. There were cases where participants were responsible for referencing multiple themes and so the number of references does not always equal the number of participants. In the older people's group, some participants exited the questionnaire before completing the open questions. The number of participants completing the open questions in these groups is displayed in the figure table title.

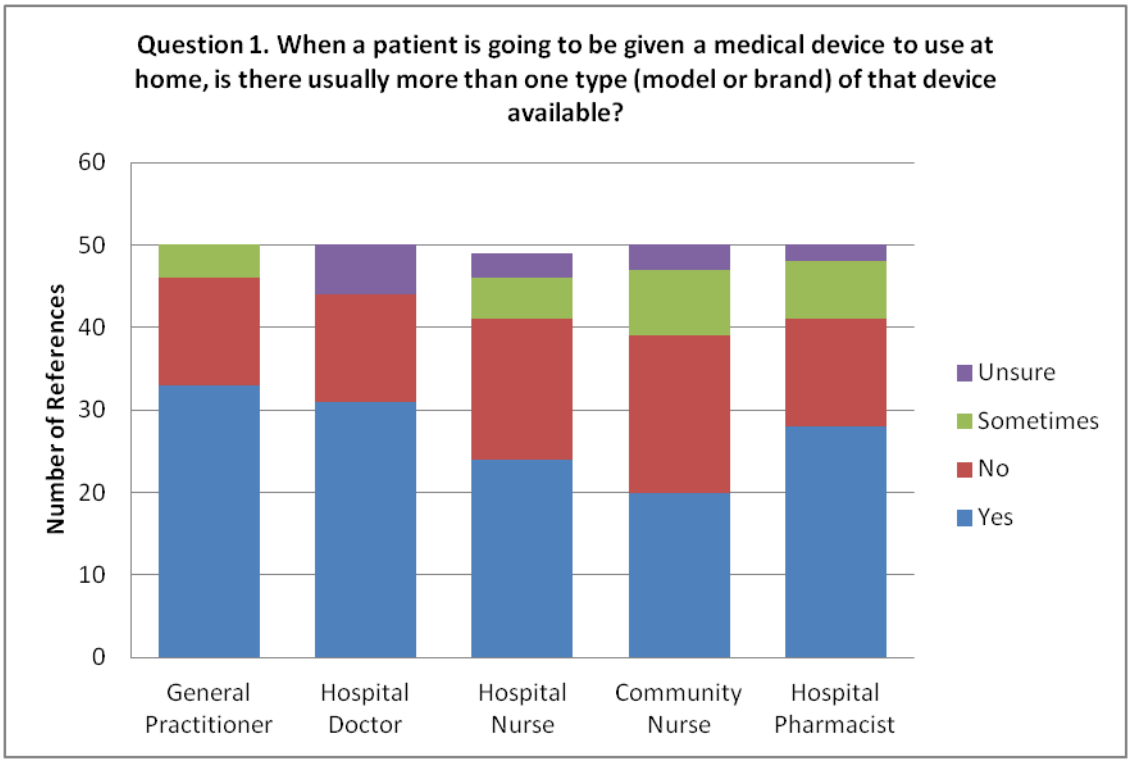

Figure 5.3 Question 1 Main themes (*and number of references*) by professional group (n=50 in each group)

The figure 5.3 shows that the majority of the professional groups report that there are usually different types of medical devices available to be given to patients to use at home, although there were still a considerable number of references to the lack of availability of alternative devices.

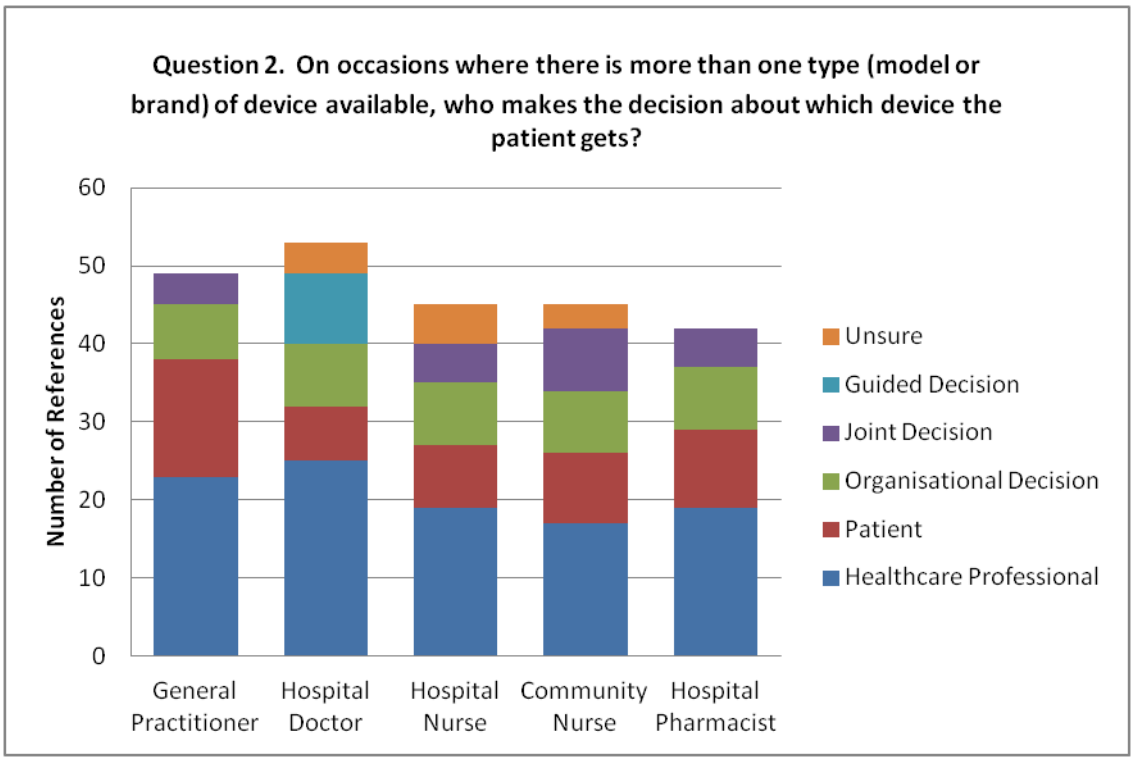

Figure 5.4 Question 2: Main themes (*and number of references*) by professional group (n=50 in each group)

Most of the references in answer to question two suggest that the healthcare professional plays a larger role in determining which medical devices are given to patients than the patients themselves. This supports the proposition of a more paternalistic approach to medical device provision discussed in the previous section. Participants also referenced the role of the healthcare organisations in decisions about the provision of medical devices.

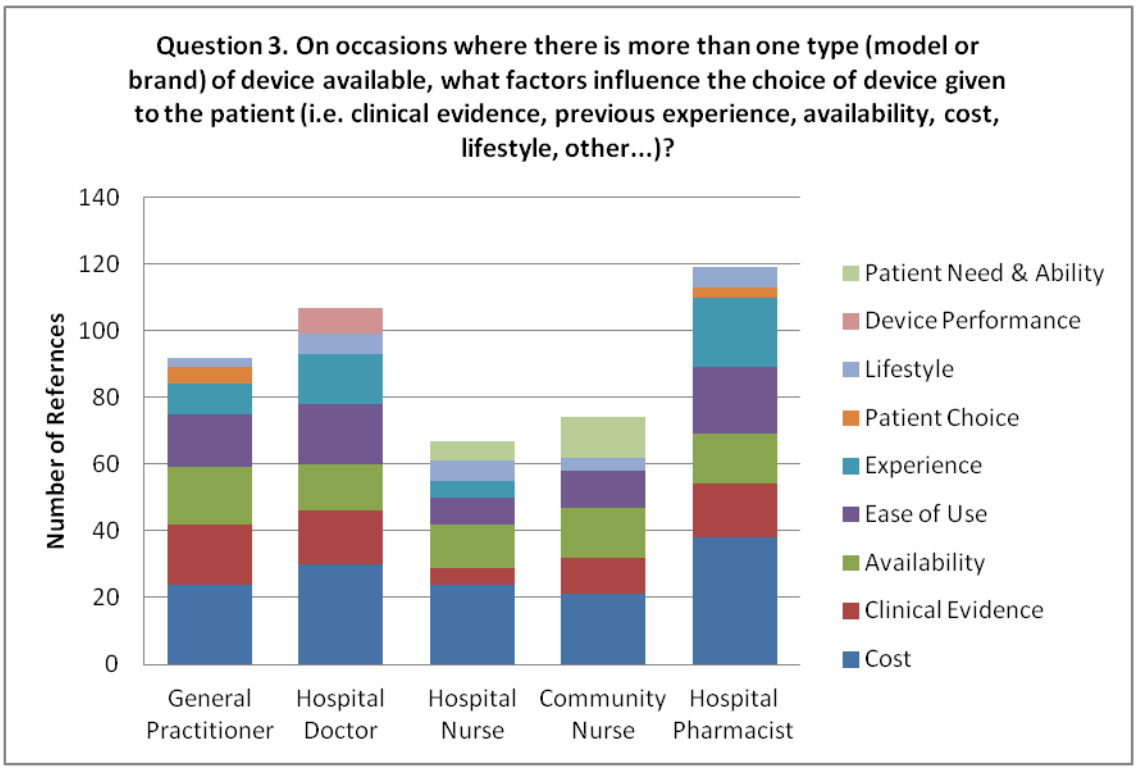

Figure 5.5 Question 3: Main themes (*and number of references*) by professional group (n=50 in each group)

Figure 5.5 highlights the importance of cost as an influence in deciding which medical device is given to patients across all participant groups. Similarly, all groups reference the availability of devices to be an influencing factor. There were few references to patient choice and lifestyle factors as being influencing factors.

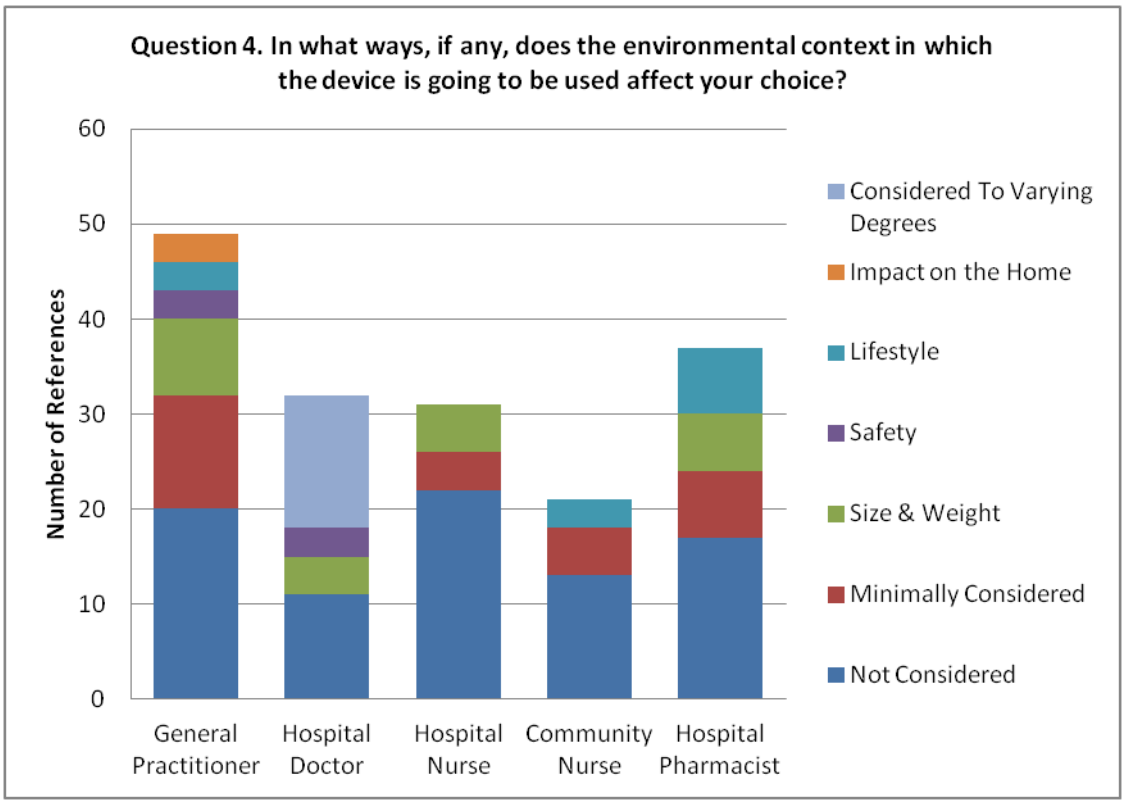

Figure 5.6 Question 4: Main themes (*and number of references*) by professional group (n=50 in each group)

Overall, the references in figure 5.6 show that the there is little consideration given to the environmental context in which the device is going to be used. This supports the findings from the forced choice question in the first section of the questionnaire. There were, however, some references to the physical characteristics of devices as playing a part in device choice.

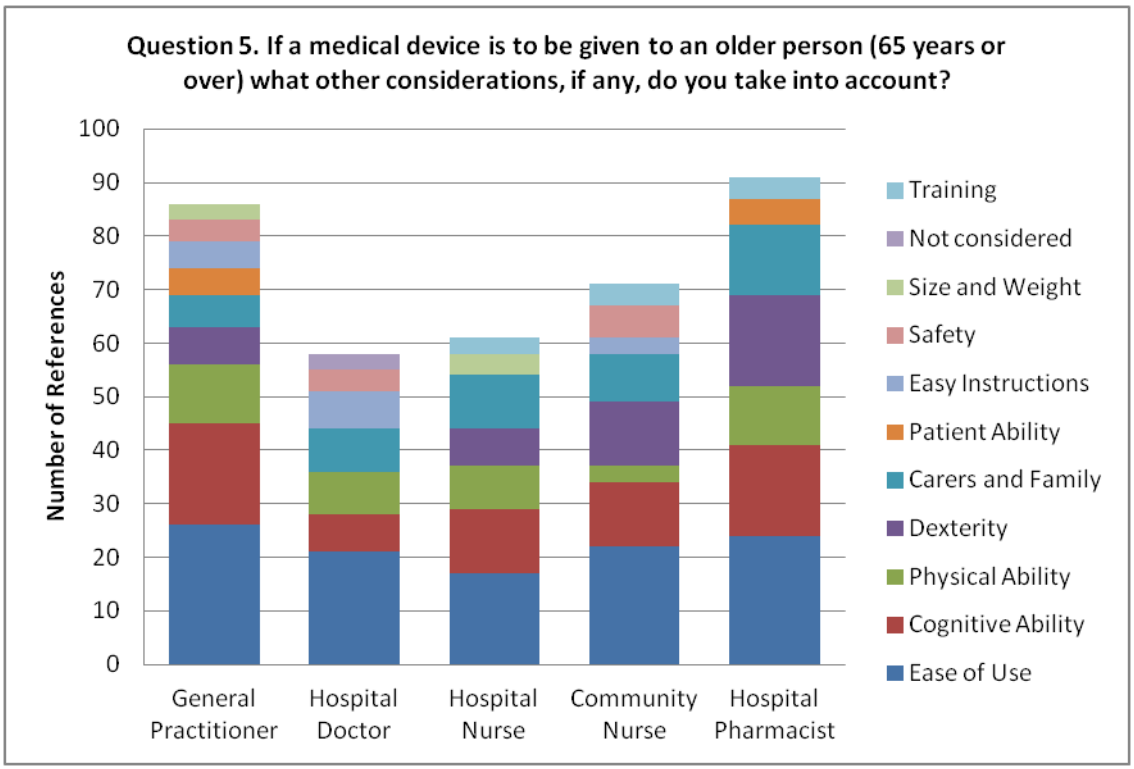

Figure 5.7 Question 5: Main themes (*and number of references*) by professional group (n=50 in each group)

Ease of use and cognitive abilities were highly referenced across the participant groups as considerations taken in to account when giving devices to over 65s and all groups took into account carer and family issues to some degree. There were relatively few references to issues around training and instructions given the high ranking of these factors in the forced choice section of the questionnaire.

Question 1.	Part a Themes	Part b Themes
If you had to use a medical device at home would you like to be given a choice between different models? If so what sort of things would you take into consideration when making that choice?	Yes *(Ref 34)*	**Ease of use** *(Ref 25)*
	No *(Ref 3)*	**Home & lifestyle** *(Ref 23)*
	Don't Know *(Ref 2)*	**Effectiveness** *(Ref 16)*
		Easy to maintain *(Ref 5)*
		Easy Instructions *(Ref 3)*

Figure 5.8 Over 65s non-users (n=39) question 1 main themes (and number of references)

Figure 5.8 shows that non-users overwhelmingly expressed a desire for choice over different models of medical device and referred to ease of use and home and lifestyle as factors that they would take in to account when making that decision. According to the answers given by healthcare professionals to questions two and three, it is the medical professional that choose the medical device and that home and lifestyle factors are rarely considered when making that choice

Question 2.	Part a Themes	Part b Themes
If you had to use a home use medical device, would you look into the different types that are available? If so how would you do so?	Yes *(Ref 38)*	**On-line sources** *(Ref 26)*
	No *(Ref 1)*	**Advice from Healthcare professional** *(Ref 21)*
		Other users *(Ref 4)*
		Printed materials *(Ref 3)*

Figure 5.9 Over 65s non-users (n=39) question 2 main themes (and number of references)

Figure 5.9 shows that the majority of respondents would investigate potential devices available to them, with many referencing the use of online resources as an avenue of research with a similar number of references taking advice from healthcare professionals.

Question 3.	Themes
When healthcare professionals recommend or provide a home use medical device what factors do you think they consider before making that recommendation?	**Cost** *(Ref 18)*
	Effectiveness *(Ref 15)*
	Ease of use *(Ref 11)*
	Suitability for patient condition *(Ref 10)*
	Patient ability *(Ref 6)*
	Home & Lifestyle *(Ref 5)*

Figure 5.10 Over 65s non-users (n=39) question 3 main themes (and number of references)

In figure 5.10 respondents refer to cost and effectiveness as the main factors that healthcare professionals consider when recommending a medical device while there were few references to the consideration of patient ability or patient home and lifestyle. This supports the findings from the answers given by the medical professionals

Question 1.	Part a Themes	Part b Themes
Were you offered a choice between different types of the medical devices you currently use? If so, what did you consider when making that choice	No *(Ref 26)*	Home & Lifestyle *(Ref 8)*
	Yes *(Ref 10)*	Cost *(Ref 5)*
	Self-acquired *(Ref 6)*	Advice from healthcare professionals *(Ref 5)*
		Effectiveness *(Ref 3)*

Figure 5.11 Over 65s device users (n=42) question 1 main themes (and number of references)

The majority of respondents in figure 5.11 reported not having been given a choice of medical device which supports the findings from the answers given by professionals to their second question. When they were given a choice cost, home and lifestyle and advice from healthcare professionals were considered.

Question 2.	Themes
What effects, positive or negative, has the device had on your life	Symptom relief *(Ref 15)*
	Increased quality of life *(Ref 15)*
	Reassurance *(Ref 6)*
	Decreased quality of life *(Ref 5)*
	Reduced GP/clinic appointments *(Ref 4)*
	Reduced hospital admissions *(Ref 3)*

Figure 5.12 Over 65s device users (n=42) question 2 main themes (and number of references)

In table 5.12 participants' reports refer to symptom relief and quality of life as positive effects that the medical device has had on their lives. Relatively few references were made concerning reduced GP appointments or hospital admissions.

Question 3.	Themes
If you could change anything about your devices what would that be?	Home & lifestyle issues *(Ref 14)*
	Nothing *(Ref 12)*
	Improved functionality *(Ref 5)*

Figure 5.13 Over 65s device users (n=42) question 3 main themes (and number of references)

Figure 5.13 shows that home and lifestyle issues appeared to be the main criteria from which they would change aspects of their device which supports the findings that these factors are not particularly taken into account when medical devices are chosen for patients. However, a similar amount of references indicated that they would not change anything about their device.

5.3.4 Discussion

While the 'satisfaction' factors concerning choice, appearance and the impact on the home environment were consistently ranked low by all participant groups in the forced choice section of the questionnaire, the answers to the open questions indicated that they were either not without some value to participants or had some effect on behaviour.

On the whole the professional groups reported that there was often more than one type (model or brand) of a particular medical device available that could be given to patients to use at home, but the choice of which device the patient is

given is usually made by the healthcare professional. This supports the suggestion made in the previous section that a more paternalistic approach has been adopted when selecting medical devices. Medical professionals working in hospitals also refer to it being an organisational decision so what they can offer may also be limited by what is made available to them.

When asked about what factors influence the choice of medical device provided to patients, healthcare professionals predominantly reported cost as a major factor. While consideration was also given to the clinical evidence associated with the device, availability (possibly in terms of the organisations decision to supply one particular device related to cost) was also highly referenced by participants. This indicates that while medical professionals practice with a certain amount of autonomy, their actions may be limited in terms of the overall aims and priorities of the healthcare systems that they are a part of.

When the device was to be given to an older person, ease of use was a common theme in the answers given by all of the professional groups. Other highly reported considerations were the cognitive abilities and the physical limitations of the intended user. The environmental context in which the device is going to be used was not particularly considered although community nurses referred to the compatibility with the home more than other professional groups.

Some of the answers given to these questions by the professional groups run counter to what the participants who were 65 or over would actually consider themselves in a medical device. As expected from the answers given by the professionals, the majority of device users report not being given a choice over medical devices given to them to use at home. However, those that had a choice seemed to consider home and lifestyle factors when making that choice. When asked about what they would change about their device, again factors associated with making the device more compatible with 'home and lifestyle' featured highly.

Participants who were users of medical devices in the home reported more instances of positive rather than negative aspects related to their device. These

were grouped into themes related to quality of life and symptom relief. There is evidence of an association between health related quality of life and patient satisfaction (Aharony & Strasser, 1993; Asadi-Lari et al., 2004). The link between these factors supports the idea that, in general, device users seem satisfied with their devices, which supports the findings from the first study. However, in relation to the discrepancy model of satisfaction discussed previously this does not imply that their devices were 'good devices' only that the devices were not particularly bad.

For non-device users, most reported that they would like a choice if they had to use a medical device (where in practice, according to the answers given by the healthcare professionals, it would be unlikely that they would get a choice). If participants were to look into different types of medical devices they may have to use, most participants reported that they would take advice from healthcare professionals or use online sources. It has been suggested that in excess of 70% of internet users in Britain search for health information online (Dutton & Blank, 2011), however, older adults are less likely than other age cohorts to access the internet for health related information (Colorafi, 2014). There were a relatively high number of responses in relation to the intended use of online resources, as opposed to printed materials, in relation to researching the different types of medical devices available. This may be explained by the fact that the questionnaire was distributed online and so the respondents were more likely to be familiar and comfortable with the internet.

While non-device users acknowledged that healthcare professionals would be more likely to consider cost and effectiveness when recommending a medical device to be used at home (possibly because it is seen as the role of healthcare professional to consider these things), ease of use as well as home and lifestyle factors featured prominently in the things that they would consider themselves when making that choice. Interestingly this is not supported by the findings from the forced choice part of the questionnaire (see table 5.2). This particular participant group ranked 'instructions are sufficient to enable correct use' more important than 'the device has little impact on the home environment'. This

highlights the difficulty of using questionnaires to investigate complex issues and suggests that the importance of different device characteristics in general is not the same as the characteristics that they would personally consider when making a choice.

It is important to point out that the presentation of the ranking options may have influenced what was reported in the open questions. While there was randomised presentation of the quantitative questions and options, participants may have been focussed on those options when answering the open questions. The greater number of factors relating to the practicalities of using medical devices, and conversely, the novelty of the 'satisfaction' factors may have unduly prejudiced participants' answers to the open questions. The effect of this may have been mitigated by randomising the presentation of the open questions either before or after the paired comparison section of the survey.

5.4 Limitations

One limitation of this questionnaire is that it restricted participants to responding about just one medical device when there is inherent variability within the types of medical devices that can be used in the home environment. This resulted in the answers applying to a wide range of medical devices. While this may add to the generalisability of the results, it may be that certain characteristics or factors are more important to different types or classes of home use medical devices which would not be discernible in the present study. A way of categorising different medical devices that are used in the home (e.g. treatment delivery vs condition monitoring, life sustaining vs life prolonging, permanent or temporary) may need to be developed in order to ascertain whether the reported importance of the different characteristics or factors changes in relation to the different categories of devices. It may, on reflection, have been better to ask all participants to answer the survey questions in relation to one particular medical device.

Although the questionnaire was piloted there may have been some ambiguity in the interpretation of certain characteristics, for example, did healthcare

professionals and medical device users/non-users attach the same meaning to the idea of 'cost effectiveness'?

Another limitation may be the use of an online only survey when recruiting older people as participants. Internet use in people aged 65 years and over is only 39% with fear of the internet and technology being a major factor in non-use of the internet (Dutton et al., 2013).This could mean that the responses of participants in these groups were not necessarily representative of older people who were not internet users. The cost, time and practicalities of using a paper based version of the survey for the groups of older people would have been prohibitive on this occasion.

In relation to the thesis as a whole, the device factors/characteristics that were the focus of the questionnaire would ideally have been compiled from the qualitative studies in chapters four and six. However, due to the longitudinal design of the study in chapter six and the complexities of designing and distributing the finished questionnaire within the timeframe of the PhD, this was not possible and as a result the aforementioned studies took place concurrently. This may have led to important device characteristics not being included in the survey.

While efforts were made to simplify and pilot this questionnaire it may be that the complex nature of the subject under investigation meant that the questionnaire as a research tool was not sensitive enough to detect differences between the groups. On reflexion a larger pilot study and gathering feedback could have been conducted to test the questionnaire which may have identified any weaknesses. This would have allowed any ambiguities in the wording of questions and what participants were considering when they answered the questions to be identified which would have allowed the opportunity to make further refinements or change strategy such as conducting interviews of focus groups.

5.5 Summary and contribution of this research

This study set out to discover which factors associated with medical devices that are used in the home are considered the most important by the different healthcare professionals responsible for supplying them and people who either use or do not use medical devices in the home.

The hypothesis that doctors and nurses in primary care would be more likely to consider the home environment as an important factor when selecting a medical device for an individual than hospital based, secondary care practitioners was not supported.

The characteristics ranked highly by participants seem to be related to the practicalities of medical device use which is more in keeping with a traditional approach towards promoting compliance with treatments to improve clinical outcomes. The ranking of characteristics in the lower part of the table appeared to be concerned with device satisfaction. The reason for the low ranking of these characteristics was less clear given that the open questions in the questionnaire suggested that they may have some bearing on participant behaviour (in terms of what they would consider when choosing a device) and the qualitative literature focusing on medical devices suggests these issues are important to device users.

The proposal of models of care and government policy commitments concerning a more multi-disciplinary, person centred delivery of care for people with chronic diseases has been espoused in the literature. This study, however, has suggested that at least as far as medical devices are concerned, a more paternalistic approach as to what is important in selecting a device has been adopted. This study not only supports the findings of Coulter and Ellins (2006) and Stiggelbout (2015) in relation to the importance of patient-focused interventions but has highlighted a specific area, namely home medical devices, where patient choice and empowerment is seemingly lacking. This has implications for the medical

management of chronic conditions discussed in the literature review in terms of improving the health and quality of life of those who have long-term conditions.

Chapter 6: Adjusting to life with an oxygen concentrator

6.1 Introduction

This chapter presents the results of a longitudinal, qualitative interview study and the implications of this study for this research. The aim of this study was to answer the research questions posed at the end of the literature review in chapter two and in particular to explore the question:

What is the lived experience of couples who are given a medical device to use at home and how does this change over time?

The study described in chapter four and the literature review have both demonstrated that medical devices are intrusive and may impact on the different 'aspects of home', thereby requiring users and partners to make adjustments to the way that they live in their own homes. However, what is not known is whether the issues raised are stable but also how any the effects and adjustments develop/change over time are likely to change over time.

It was decided that interviews would be carried out with couples where one person had been diagnosed with chronic obstructive pulmonary disease (COPD) and the prescribed treatment was to use an oxygen concentrator in the home, in order to manage their symptoms.

6.2 Background

Chapter four described how a variety of different medical devices are integrated into the homes and lives of device users and their partners. The in-depth experiential aim of this study required the selection of one particular medical condition and device. As the interviewing of couples provided such rich data in the first study and because of the importance of dyadic coping and adjustment discussed in the literature review, it was decided to continue with this approach. It was also decided that in order to capture changes in experience, both the

condition and the device chosen to be the focus of this study should have the potential to exert significant influence on both the device user and their partner. The nature of the devices used in COPD combined with the fact that many of the emergent themes from study one were relevant to these devices provides justification for the focus on COPD.

6.3 Chronic obstructive pulmonary disease

Chronic obstructive pulmonary disease (COPD) is a global health problem which is currently the fifth leading cause of death worldwide and is expected to become the world's third leading cause of mortality by 2030 and a major source of economic and social burden (WHO, 2016).

COPD can be defined as:

> *"A common preventable and treatable disease [that] is characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lung to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients" (Global Initiative for Chronic Obstructive Lung Disease, 2014).*

COPD is the umbrella term for a collection of lung diseases including emphysema and chronic bronchitis (DoH, 2011). The changes in the lungs as a result of these diseases are illustrated in figure 6.1. Emphysema is where the walls between air sacs (alveoli) have been damaged causing the sacs to lose their shape and often results in creating fewer and larger air sacs instead of many tiny ones. As a result, the lungs are less efficient at getting oxygen into the body and removing waste carbon dioxide, which leads to shortness of breath (dyspnoea) and patients having to breathe harder. Chronic bronchitis is characterised by inflammation and irritation to the lining of the airways (bronchi), which causes the lining to

thicken and the production of thick mucus or phlegm. This makes it difficult to breathe and causes a productive cough (British Lung Foundation, 2013).

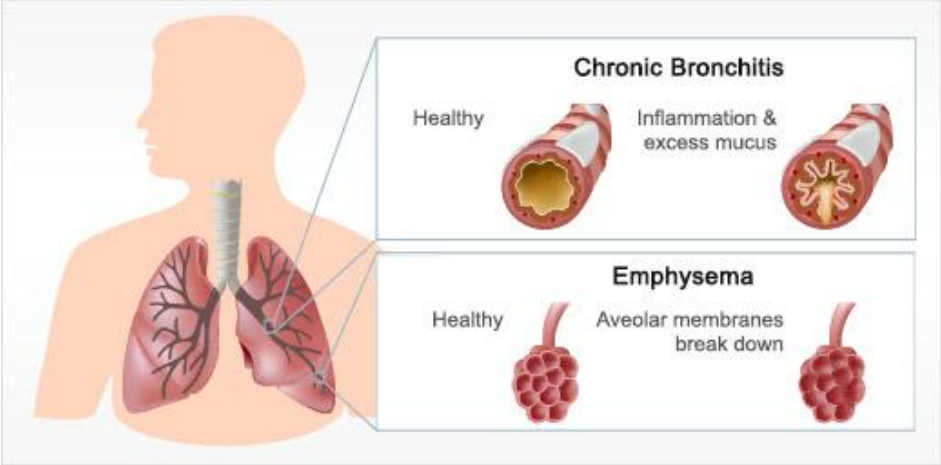

Figure 6.1 Changes in the lungs as a result of Emphysema and chronic bronchitis (source: The Mesothelioma Center, 2015)

The main symptoms of COPD are shortness of breath, reduced exercise tolerance, regular sputum production and wheezing. While these symptoms may not change markedly over several months, the long term deterioration of the condition has an adverse effect on a person's ability to carry out activities of daily living and quality of life (DoH, 2011). People with COPD are also prone to acute respiratory exacerbations which are characterised by symptoms of worsening airflow obstruction and associated breathlessness, cough and both sputum purulence and production. These exacerbations, linked to viral or bacterial infections, often result in unscheduled visits to general practitioners or hospitalisation and are normally treated with a course of antibiotics and corticosteroids (Donaldson et al., 2002).

It is estimated that COPD is responsible for around 30,000 deaths each year in the UK and that around 3 million people in the UK are living with COPD, although 2 million of those remain undiagnosed (Healthcare Commission, 2006; Health and Safety Executive, 2013). The total direct annual cost of COPD to the NHS in 2000-1 was estimated to be around £982 million which includes the cost of

primary and secondary care, community based services and medications (NICE, 2010).

A diagnosis of COPD is made based on of evidence from medical history, physical examination and the presence of airways obstruction as confirmed by spirometry (a test that measures the volume and flow of air from the lungs (DoH, 2012)). Air flow obstruction in COPD is not fully reversible and does not change significantly over several months. Spirometry uses the ratio between the forced expired volume in 1 second (FEV_1) i.e. how much air a person can expel from their lungs in 1 second and the forced vital capacity (FVC) i.e. the total amount of air a person can expel from the lungs after a maximum inhalation to define COPD. COPD is diagnosed when the FEV_1/FVC ration is less than 0.7 and the FEV_1 is <80% predicted. COPD may still be diagnosed if FEV_1 is ≥80% predicted in the presence of respiratory symptoms. Severity of airflow obstruction is designated mild, moderate, severe and very severe by ≥ 80%, 50-79%, 30-49%, and <30% of FEV_1 respectively (NICE, 2010).

Long term oxygen therapy (LTOT) is established as the only therapy proven to alter the course of later stage COPD by improving survival rates in patients with severe COPD who use oxygen for at least 15 hours a day (Nocturnal Oxygen Therapy Trial Group, 1980; Stuart-Harris, Bishop and Clark, 1981). Home oxygen therapy can be delivered via compressed gas in metal cylinders, liquid oxygen that can be decanted into portable containers or stationary oxygen concentrators. The most common and cost effective way to deliver oxygen for LTOT patients is by using an oxygen concentrator (see figure 6.2 for an example). These concentrators run off mains electricity and work by forcing room air through a series of filters to remove nitrogen and other low-concentration gases, thus concentrating or enriching the oxygen levels in the resulting product. This can then be delivered to the patient either by oxygen mask or nasal cannula (see figure 6.3) (Gibbons, 2002).

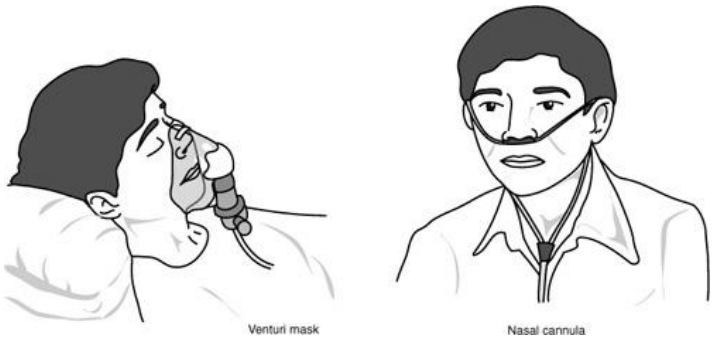

Figure 6.2 Oxygen mask and nasal cannula

(Rinehart, Sloan and Hurd, 2010)

Figure 6.3 An Airsep ® Newlife Elite 5 Litre Oxygen Concentrator (source: Intermedical.co.uk)

The assessment of patients for LTOT involves the measurement of arterial blood gasses. This should take place on two occasions at least three weeks apart where there is a confirmed diagnosis of COPD and patients, whose condition is stable, are receiving optimum medical management. LTOT is indicated in patients who have a PaO2 (partial pressure of oxygen in arterial blood) consistently at or below 7.3 kPa or they have a PaO2 between 7.3 kPa and 8 kPa, together with the presence of one of the following: Secondary polycythaemia (where too many

red blood cells are produced as the result of an underlying condition) or evidence of pulmonary hypertension (NICE, 2010).

Prescriptions for all types of home oxygen therapy need to be made on a 'Home Oxygen Order Form (HOOF)'. This form will then be sent by Fax to the contractor, who will organise delivery of oxygen to the home. In some instances, as well as the concentrator, a small portable cylinder may be provided to take oxygen outside of the home (British Thoracic Society, 2006). In England there are four companies that provide home oxygen services for the NHS each covering a certain geographical area and each supplying slightly different types of oxygen concentrator. Providers should ensure patients/carers receive on-going training and written information concerning equipment use and treatment management. From 2011, the contracts with the device providers also impose an obligation to ensure that any improvements or innovation in relation to such equipment are adopted rapidly. Healthcare professionals are also required to review patients at home after four weeks to enable re-assessment of the person's clinical status, adherence to the oxygen therapy regime (including the appropriateness of the equipment) and review safety (DoH, 2012).

The aim of LTOT is to prolong survival not to alleviate breathlessness. Where symptoms of breathlessness have been assessed, there has been little, if any, improvement associated with LTOT (Booth et al., 2004). Research has, however, indicated the LTOT may be significantly associated with improvements in health related quality of life (Eaton et al., 2004) reduced hospital admissions (Ringbaek et al., 2002) and improvements in mood and attitudes (Borak et al., 1996). Despite these benefits it is estimated that adherence to LTOT for the prescribed time of ≥ 15 hours a day ranges from 45% to 70% (Katsenos & Constantopoulos, 2011). This, coupled with sub-optimal prescribing of LTOT has considerable cost implications for the NHS (DoH, 2010b). In an attempt to classify all the possible factors, Cullen (2006), identified two areas implicated in poor adherence to oxygen therapy. The first area concerned 'Illness factors' (illness characteristics, treatment complexity and attitudes toward LTOT), while the second area

concerned ‘personal/family factors’ (demographic factors, patient/family functioning and cognitive factors).

Previous qualitative research has also described some of the benefits and problems associated with COPD and long term oxygen therapy. Goldbart et al., (2013) conducted focus groups and interviews with patients who were prescribed LTOT, their informal carers and healthcare professionals. Patients and informal carers identified positive aspects to their treatment in terms of the social benefits of being able to leave the house more and feeling better able to manage their daily lives. This, however, was offset by the stigma associated with the equipment and the perceived dependency on the therapy. The health professionals in that study expressed concern when oxygen therapy equipment prescribed to service users was not used and the inappropriate prescription of LTOT - they saw their role as to improve the way LTOT was being used by patients, but also to influence the service provided by professional colleagues.

Ring and Danielson (1997) similarly reported conflicted feelings expressed by patients with experience of LTOT, with patients describing how they have to ‘put up with’ and ‘tolerate’ LTOT in order to survive. This illustrates that the restrictions that the therapy imposes should also be considered alongside the advantages the oxygen has on the body. This study goes on to underline the need for greater efforts to be made by nurses in terms of patient education to encourage treatment acceptance. Godoy et al. (2012) suggests that knowledge of patients’ home conditions can help to identify problems and be useful in tailoring patient education that may improve the way LTOT is used in terms of treatment duration, smoking cessation, concentrator maintenance and cleaning.

The experience of carers and partners of people living with COPD has also been explored. Bergs (2002) described the experience of women caring for husbands with COPD. The effect of COPD on the wife-caregivers’ quality of life was profound. Themes that emerged from the interviews included: not having time to worry about their own health, a weakening of the marital relationship, living in an emotional straitjacket, walking the road with him to the very end and the

prospect of adjusting to a single life. This led Bergs to conclude that nurses have a responsibility to help wives whose spouses have COPD to attain the best quality of life possible within the limits set by the husband's illness and disability. This, it is suggested, may be achieved by managing expectations and better preparing the wife to anticipate the problems and deal with them better. This research only considered women caring for husbands and made no recommendations as to the effect of managing the expectations of the male patients who had COPD.

Kanervisto et al. (2007) used a quantitative research method to compare family dynamics in families of COPD patients without oxygen therapy with families of COPD patients with LTOT. They found that family dynamics in families with LTOT were notably worse in the dimensions of communication (i.e. distorted communications and unclear perceptions) and roles (including role reciprocity, which is the reciprocal contribution of skills, helping, or resources according to their role in the family and role conflict, which is where a person is expected to play two incompatible roles) but better in terms of individuation (having a clear self-concept), mutuality (having a connection with others), flexibility and stability. The dysfunction in the nature of roles and communication in the families with LTOT seems to support some of the experiences of care-giving wives reported by Bergs (2002). Dysfunctional dynamics in families with severe COPD may weaken the ability of those families to manage in everyday life (Kanervisto et al., 2007).

6.4 Study design

Central to the provision of LTOT is the concentrator itself and it is the effect of this device on the lives of both patients and partners that is the focus of the current study. While participants in the previous studies have been on oxygen therapy for some time, the aim of this study was to follow couples as they begin long term oxygen therapy and to describe their experience. To achieve this a longitudinal qualitative interview design was adopted.

6.4.1 Longitudinal design

Longitudinal qualitative studies have been widely used in specific areas of sociology such as anthropology, community and education studies, family studies and age cohort studies (e.g. Bynner & Joshi, 2007; Pollard & Filer, 2007; Kemper & Royce, 2002). Interest in longitudinal methods is growing and this approach is becoming more popular and valued within the wider social sciences community (Elliot et al., 2008). However, while many qualitative studies have utilised different elements from longitudinal research (i.e. re-interviewing or returning to the same research sites), *"what distinguishes longitudinal qualitative research is the deliberate way in which temporality is designed into the research process making change a central focus of analytic attention"* (Thomson et al., 2003 p185). In this way what makes research longitudinal has little to do with how long the study is conducted over, it may be weeks, months or years, rather it is capturing change that is the main concern.

Looking for, describing and understanding change over time requires some acknowledgement of the different ways we understand the terms 'time' and 'change' (Corden & Millar, 2007). The construct of time can be considered in different ways. Time does not have to be thought of in a physical sense (i.e. clocks, calendars, the rotations of planets or the oscillating of atoms) but can also be a culturally constructed as well as an individually and subjectively interpreted construct (Saldana, 2003). Time can also be framed in respect to the life course and the historical events and period in which this takes place (Brannen & Nilsen, 2006).

Change has been described as contextual and multifaceted and that:

> *"Useful research on change should explore the contexts, content, and process of change together with their interconnections through time. The focus is on changing, catching reality in flight; and in studying long-term process in their contexts"* (Pettigrew, 1990 p268).

Saldana (2003) highlights the difficulty in capturing the meaning of change by asking whether synonyms such as 'evolution', 'alteration', 'transformation', 'disturbance' or 'modification' help or hinder in this endeavour. While change is whatever the researcher defines it to be for each particular study, Pettigrew (1990) highlights the importance of explicitly defining what change means in the study research design. However, in some studies it is not always clear what type of change process to look for (especially those studies using an inductive framework) or other more subtle change processes could be overlooked if attention is too focused in another area. Thus there is also a need for flexibility and to allow the definition of change to emerge from the analysis: *"We should permit ourselves to change the meaning of change as the study progresses"* (Saldana, 2003 p 10).

The inductive and experiential nature of this study did not set out to look for particular aspects of change (psychological, practical, health status etc.) but was intended to be open to any types of change that may occur.

6.5 Method

6.5.1 Participants

Following approval by the National Health Service Research Ethics Committee (reference: 12/EM/0388), four couples were recruited from an oxygen assessment clinic in the East Midlands. The inclusion criteria were that couples were aged 65 years or older and that one person in each couple had been assessed by the clinic as requiring an oxygen concentrator to be used in the home as a result of their COPD. Participants were excluded if they lived in nursing or care homes as it was thought that medical devices would be more readily accepted in these types of establishments. All participants had to be able to consent to taking part and interact verbally in English.

The intention was to interview the couples prior to receiving the device to capture the essence of change from not having to having the device in the home and the initial adjustments needed to accommodate this change. However, in

reality this was extremely difficult due to the very short time period (3 working days) between the decision to prescribe the device and the device being delivered into the home, which left only a small window for an interview to be arranged at a mutually convenient time. In addition, the number of participants meeting the criteria for LTOT during the recruitment period was low and as a result, participants were recruited who had already received the device (up to two months previously). These participants had typically been given the device as a condition of their discharge from hospital following an exacerbation of their condition and were seen in clinic to assess the continued suitability of the device once their condition has stabilised.

While it was hoped that between six and eight couples would be recruited to participate in this study, the difficulties outlined above and the time pressures associate with conducting and analysing longitudinal research meant that only four couples were included. The implications of this will be discussed in the limitations section of this chapter.

The concentrators encountered in this study were typical of the ones provided by the NHS. They were grey in colour, approximately 70 cm tall (similar to the size of a bedside cabinet) and generated noise levels equivalent to that of a dishwasher. They weighed 25 kg and had castors, although in reality, the participants in this study did not need to move the device around as they were provided with enough plastic tubing to facilitate movement throughout the house both upstairs and downstairs. The patients had been instructed to use the concentrator for at least 15 hours a day and it was recommended to them that using the concentrator overnight would be the easiest way to achieve this. Two of the participants made the decision to use the device 24 hours a day.

6.5.2 Data Collection

Potential participants who met the inclusion criteria were first approached by the assessment clinic staff to ascertain if they were happy to be approached by the researcher to explain more about the study. Participants who expressed an

interest in taking part were provided with an information sheet, which explained the aims of the study, what was required of them and how issues of confidentiality, anonymity, data storage/disposal and the right to withdraw from the study and their data removed would be addressed. Contact details were taken and participants were contacted the next day to arrange the first interview. This allowed a cooling off period so that participants did not feel pressured to take part in the potentially emotive environment of an assessment clinic. It was felt that this would also lessen any feelings of obligation to the researcher or clinical staff to take part in the research.

All the interviews took place in participants' homes and where possible device users and their partners were interviewed together. It was acknowledged that the interviews would be different depending on whether the couple were interviewed together or separately. It was also anticipated that the narrative of the partners would overlap to varying degrees, depending on their relationship, but would not completely match the account of the other (Taylor & de Vocht, 2011). This is because, from a hermeneutic phenomenological perspective, their 'being in the world' is informed by their individual history (Heidegger, 1996).

The first interview was conducted one day prior to device delivery for one couple, three days post-device delivery for another couple and six weeks post-delivery for two couples. The second interview was scheduled to take place a month after that and the final interview four months after that. However, due to the unpredictable nature of peoples' health needs, the schedules did need to be slightly altered (see table 6.1). Consent forms were completed prior to each interview to ensure continued understanding of the process and that participants were willing to continue. Inconvenience payments of shopping vouchers were given to couples after each interview of increasing value: £20 after the first interview, £30 after the second and £50 after the third interview.

Consistent with a phenomenological approach to analysis where the emphasis is on attempting to understand the psychological experience of participants, the use of semi-structured interviews are particularly useful (Smith, 1995) The semi-

structured interview provides much greater flexibility than other data collection methods (e.g. questionnaire/survey, structured interview) as it allows the researcher to follow up areas of interest presented by the participants that might not otherwise have emerged. This format then allows the interview to be guided by the participant rather than the schedule and allows the interviewer to attempt to enter the psychological and social world of the respondent.

	Pseudonym	Age	Interview 1	Interview 2	Interview 3
Couple 1	Ray (device user)	75	3 days post device delivery.	4 weeks after 1st interview	7 weeks after 2nd interview Device had been removed from home
	Rita (partner)	69			
Couple 2	Sally (device user)	65	6 weeks post device delivery	4 weeks after 1st interview	4 months after 2nd interview
	Stan (partner)	65			
Couple 3	Tracy (device user)	84	1 day prior to device delivery	4 weeks after 1st interview (told to stop using device after 2 weeks)	No 3rd interview due to device removal
	Terry (partner)	82			
Couple 4	Wilma (device user)	69	6 weeks post device delivery	4 weeks after 1st interview	4 months after 2nd interview
	Wally (partner)	69			

Table 6.1 Participant demographics and interview timings

The semi-structured interviews were each guided by an interview schedule consisting of open-ended questions (see appendix four). Some of the questions were broad and exploratory in nature and were followed up with more focused prompts when required. The interview began with questions regarding how COPD affected both their lives. This was followed by questions about the oxygen concentrator, which aimed to encourage participants to consider: how they felt about the device, if their life and identity has changed since owning the device and what, if any, changes they would make to the device.

The research interview has been defined as a 'professional conversation' as its primary aim is to elicit information from participants (Kvale, 1996). However, it

has been suggested that this method of interviewing perpetuates the disempowerment of vulnerable groups (such as older people) and that a 'conversation between equal partners' or dialogical approach should be taken (Russell, 1999). The interviews in this study relied on the second approach in terms of rapport building and breaking down barriers between interviewer and interviewee in an attempt to get participants to speak openly. When appropriate, questions were either directed to the couple or to each individual in turn. This conversational approach allowed couples the freedom to not only contribute their individual recollections to the construction of an agreed version of events but also to openly disagree and highlight the defining differences in their experience of living with the device. There is also evidence that when long-term intimate couples participate in social exchanges there are benefits of richer, more vivid descriptions of autobiographical events (Harris et al., 2014).

Interviews lasted approximately 60 minutes. The interviews were recorded digitally and were subsequently transcribed verbatim.

Paper diaries were also issued to participants to act as either an 'aide memoire' to facilitate discussions at future interviews or to provide information to the researcher that they may wish to keep private from their partners. There was no insistence that these were used as it was felt that to do so would reinforce the authority of the researcher while diminishing the egalitarian status of the situation that was being sought. Only one participant utilised the diary.

6.5.3 Analysis

An in-depth approach to thematic analysis of the interview data was used to identify, analyse and report the themes within the data which was shaped and informed by Smith's (1996) interpretative phenomenology. This approach encourages a detailed examination of how people make sense of life experiences.

Unlike the thematic analysis described in chapter four which used computer software to assist with data management, it was decided that for reasons of

simplicity and flexibility, analysis would be paper-based. This consisted of six steps:

Step one - the first interview transcript from the first couple was printed out and read several times. This facilitated the researcher to become immersed in the data and begin the process of entering the participants' life world.

Step two began the initial level of analysis. The researcher went through the transcript a few lines at a time and made exploratory notes in the left hand margin or underlined anything within the text that appeared interesting or significant. This process had a phenomenological focus that remained close to the participant's explicit meaning. The phenomenological focus of these notes described the things that mattered to the participants and what those things *meant* to them.

Step three involved translating those initial notes into emergent themes. Concise themes were produced that captured the researcher's interpretation of meaning grounded in the participant's words. These emergent codes were then written in the right hand margin of the interview transcript.

Step four entailed analysing how the emergent themes fitted together to produce super-ordinate themes. These super-ordinate themes highlighted the most interesting and important aspects of the participant's account. Theme names were transferred to colour coded strips of paper and placed to one side.

Step five was the repetition of the previous steps for the next case. In an attempt to treat each case on its own terms, ideas emerging from the previous case were 'bracketed' off as much as possible so that each of the 11 interviews was treated as far as possible as separate entities. Transcripts were analysed in an order that was most convenient and time efficient rather than chronologically or grouped by couple.

Step six entailed looking for patterns across cases at a more theoretical level. This step was started when the previous steps had been completed for all of the

interview transcripts. This involved bringing together the colour coded strips of paper and sorting and arranging them on a table top (see appendix 5). Connections were considered within participants (over time) and also across couples. These higher level super-ordinate themes were only considered if they were prevalent in over half the couples (as recommended by Smith, 2011) and were related to issues surrounding the oxygen concentrator.

Thematic analysis has no set criteria for determining the prevalence of themes within the data (Braun & Clarke, 2006), however, due to the small sample size of this study sufficient information regarding participants, recruitment, analytic method and results that makes clear the journey from data to conclusions is particularly important to allow judgement, comparison and synthesis of findings (Meyrick, 2006). In relation to similar methods that specialise in studies using small participant sizes, Smith (2011), notes the importance of providing some measure of the prevalence of each theme within the data corpus and suggests that for studies with 4-8 participants extracts from at least half the participants is used to support each theme. For this study the prevalence of each theme is illustrated in table 6.2 and has been supported with extracts from at least 3 couples in the text.

Super ordinate theme	Couple 1	Couple 2	Couple 3	Couple 4	Present in over half the sample
Adjusting to a new life	✓	✓	✓	✓	Yes
Making space in their lives	✓	✓	✓	✓	Yes
Negotiating new freedoms and restrictions	✓	✓	✓	✓	Yes
Negotiating changing relationships	✓	✓	x	✓	Yes

Table 6.2 Prevalence of super-ordinate themes

6.6 Results

The process of analysis produced four interrelated super-ordinate themes regarding older people's experiences of oxygen concentrator use in the home. These were (i) adjusting to a new life, (ii) making space in their lives, (iii) negotiating new freedoms and restrictions and (iv) negotiating changing relationships. The results of this study will now be presented as super-ordinate themes and sub-themes (see table 6.3) substantiated by extracts from participant interviews.

Super-ordinate themes	Sub-themes			
Adjusting to a new life	*Knowing what to expect*	*Initial reactions*	*Starting the journey*	*Along the path to acceptance*
Making space in their lives	*Making room*	*Making time*		
Negotiating new freedoms and restrictions				
Negotiating changing relationships	*Conflict/harmony*	*Increasing physical burden*	*Increasing emotional burden*	

Table 6.3 Super-ordinate and sub- themes

6.6.1 Adjusting to a new life

The longitudinal nature of this study captured the different steps or stages that participants had to negotiate to adjust to life with an oxygen concentrator in their homes. The different stages of this process are described in the sub-themes 'knowing what to expect', 'initial reactions', 'starting the journey' and 'along the path to acceptance'.

6.6.1.1 Knowing what to expect

For device users, the journey begins with knowing (or not knowing) what to expect. Three of the couples seemed to have little idea of what was being given to them; in fact they had only seen the device for the first time during the assessment in the clinic:

> ***Rita*** *". . . only that were the first day I'd ever seen one, I mean, I used to work for social services and it was always oxygen [cylinders] at the side. . . So, no I didn't really know what it was 'til I'd seen it, and when I walked in that room where I met you that was the first time I'd ever seen one."*

> ***Tracy*** *". . . What you saw me having [the assessment] yesterday, on Monday, is the only thing I've ever seen. That's the first time I've seen one of them. And I'd been on it 20 minutes I think when you came in. Something like that."*

> ***Wilma*** *". . . Like a shoulder bag you know you take [out]? Actually that is what I thought it would be! . . . I had no idea it was anything like that!"*

It was only Sally who had any idea of what to expect and the information that they had had come from other people who had experience of these types of device, not healthcare professional:

Sally *". . .And of course people that are in hospital that have had them as well, and you just get to hear about people because I used to work at the hospital so you would hear about people that were on them or going on them, and I know that they were a good thing by everything everybody else had said."*

For all of the couples in this study, the concept of oxygen therapy was not unknown. The couples had either been previously assessed for long term oxygen therapy but did not meet the criteria at that time (or were labelled borderline) or had already been using oxygen from cylinders when mobilising. This suggests that three of the participants did not actively seek out information on what to expect in terms of future treatments and may indicate the adoption of emotion-focused or avoidance-oriented coping behaviours (Folkman & Greer, 2000).

6.6.1.2 Initial reactions

The initial reactions of the participants were, not surprisingly, related to the expectations they had about the device. For three of the couples there was a real sense of shock that things had moved so quickly and they had in some way lost control over their situation.

For Ray and Rita, even though they themselves had been thinking about oxygen, the swiftness and reality of it seemed to leave them in a state of shock, so much so that they were unable to ask anyone for information in a bid to better prepare themselves:

Rita *". . . Well I was actually a bit surprised because I'd been asking, saying I personally thought [he] needed oxygen . . . for the last three or four years and every time they'd told me he didn't fit the criteria, so when they actually sent for it, I never thought he'd get it . . . That day we met you, I were a bit shell-shocked, because I wasn't expecting that at all. . . So, they said he needed it so I*

thought well we'd better get it in then . . . As I say, it was, I were quite shocked when they said they were putting him on it. I never really got to ask the questions I might have asked."

This sense of shock was even more pronounced for Tracey, which left her feeling scared. This sense of fear was disorientating in that she did not understand how she had got into this situation or indeed what, if anything, she could do next. It was as if she had lost some control over what was happening to her:

Tracy: *"I felt frightened. There was something unknown to me. I'd been on this [oxygen cylinder] for about three years and I'd really settled down to it . . . So when it was just thrown on me, because I went down to see her a full week ago, with no intention. . . Now that was on Monday . . . So naturally, when I went there and they said I was slightly under borderline and then all this was going to happen it frightened me to death … and I'm still frightened. . . at the moment I'm scared, I'm lost, I don't know what I'm going to do next."*

The repeated use of the word 'shocked' by Rita and the phrase 'just thrown on me' by Tracy emphasises just how powerless they felt due to the sudden change in situation. There was a sense of being frozen and unable to see a way forward.

These feelings of shock were manifested in the initial denial and rejection of the device for Wilma in couple 4. She associated the device with hospitals which brought home the seriousness of her condition. In fact the device was installed while she was still in hospital with an exacerbation of her COPD and was a condition of her discharge home. Wilma was particularly adamant about not needing the device or wanting it in her house and became quite angry with medical staff:

Int: *". . . you've come home from hospital and there it is. How did you feel?"*

Wilma: *"It could have been up the end of the back garden in ten seconds flat, I'm telling you, I'm not joking. I felt, no, I don't need that! . . . I just have never seen anything like it for medical things. . . . Things like that. That, to me, is like a hospital thing; should be in hospital if you've got something like that . . . I had no idea it was anything like that, I was absolutely gobsmacked when they told me. And I said to her I don't want it, I said don't bother bringing it because I don't want it! She said well you have got to have it, I said I haven't! I don't have to have anything I don't want. I said I don't want it, I am not having that all over my house."*

Couple 2 who had some prior knowledge about the device and what it entailed saw the situation in a much more positive light. For this user (Sally) the device was something aspirational and longed for. Finally being given an oxygen concentrator was exciting and a great relief from the physical struggles of her current situation. Being given the device would provide the opportunity for greater freedom around the house:

Sally: *"I mean I had hoped before that that they would give me one actually, because I had heard about them before, and I thought that would be far simpler to be able to get around than having to keep carrying that around. And then when she told me that she was going to give me one, I thought yes, great! You know I am actually going to get somewhere now. . . And I knew myself that I was getting to a state where I did need it, I could tell myself. And when they said that they were going to give it to me, I thought yes at last! . . . I just knew that it was for me, I needed one,*

it was just a matter of [the clinic] saying yes, you can have one."

This sub-theme illustrates two different coping strategies utilised by participants. Denial and rejection of the device is indicative of avoidance-oriented coping employed by Wilma. However, Sally seemed less threatened by the prospect of having to use an oxygen concentrator. This, coupled with being better informed, allowed Sally to adopt an approach-oriented or active coping strategy where her belief that a favourable outcome was possible and she could visualise how that outcome will come about.

6.6.1.3 Starting the journey

Following the initial reactions, this part of the journey describes how the couples feel about having the device in their lives in the first few weeks. Ray and Rita (couple 1) differed considerably in their acceptance of the device in these early stages compared with the other couples. The user in this couple (Ray) was particularly relaxed and seemed to take everything in his stride. This was reflected in the way he spoke about the device in the early interviews:

Ray: *"I mean you soon get used to that . . . And that's what it is. There's no effect. Is there? No. It doesn't make you cough or anything daft like that, does it? So as regards the machine, there's nothing, is there? See it's got to be okay, hasn't it? . . . So, you have to look on the bright side of it, haven't you? As I say, I can't see any bad problems, not really."*

Very quickly the device just fitted in and was accepted as part of his life:

Ray: *"It's not a problem, I mean, you don't know you're on it. Really. You don't hear [the concentrator]. You know. You would now, because I mean . . . I'm used to it. It's as if it's been there for years. Yeah."*

This easy acceptance was not necessarily shared by Rita, Ray's partner. The device had not become part of everyday life for her in the same way it had for her husband. In fact she seemed to feel as if she has no choice but to accept the device. There is, however, the suggestion from her that the device would be more readily accepted if it could be seen to have some tangible benefits:

> ***Rita:*** *"I still, still, I see it when I come in, I don't think [he] sees it's there. . . But I see it when I come in."*
>
> ***Int:*** *"And how does that make you feel?"*
>
> ***Rita:*** *"Well, I've got to accept it. I've had to accept lots of things in life . . . if I thought it was going to do him good, and we could go on holiday, then I'll accept it . . . But no, at the moment, no, I don't, no. To [my husband] it is now part of his life and part of the furniture. To me I still look at it and think. I don't think it shouldn't be here, I just think Oh dear!"*

Both Sally and Stan in couple 2 found accepting the device to be relatively easy. The reality of having the device in the home seemed to fulfil their expectations and support their initial reactions:

> ***Sally:*** *"I wouldn't say we've had to make any adjustments, have we, really? No, it's just, kind of, made things a lot easier, because I haven't got to carry that other one round. Just fits in lovely, you know, what I need . . . I feel happy at being on it. It is there, continually, I know it is … just gives me peace of mind. Better than having to carry that cylinder around all the time!"*

While Stan did not receive any direct benefit from having the device with which to help him accept the device, he was particularly pragmatic when it came to the device and his wife's needs:

Stan: *". . . I get on with it alright. It's something she's got to have and it helps her, that's it. She needs it, so if you need it you have to use it. . . It didn't really bother me, I thought it's something that she requires, she needs it, so that's how I just accept it."*

Wilma and Wally really seemed to struggle to accept the device. Having the concentrator in their lives, combined with a general worsening of her condition seemed to signify a transition from the past in to a new way of living:

Wilma: *"I don't know. I really had no idea about it, none at all. I know at the hospital it comes out of the wall, you plug it on your nose and it comes out of the wall and that's all there is to it. But at home I never envisaged – honestly, I couldn't even contemplate anything like that, I really couldn't. It's just – it's like a whole new world, isn't it?"*

Wally: *"Yeah, yeah, I was. It was like a machine. It's like I say, I didn't visualise Wilma having this on all the time. I thought she would have to have oxygen a few hours a day and that would be it, but it hasn't worked out like that, has it?"*

For the user (Wilma) the device acted as a reminder of her relatively recent active life. For her, accepting the device seemed to entail a long psychological struggle of coming to terms with this new life:

Wilma: *". . . I honestly and truly think a lot of it is psychological as well because it reminds you all the time of what you can't do, not what you can do, but what you can't do, which to me is a bigger issue than what I can do. I'd rather go back to what I used to be able to do and try and figure out ways to do things like walk, which is just a natural thing for you isn't it to walk, shower, clean, cook, I*

just want to think that's what I should be doing. I shouldn't be walking around with this. I should be doing all those things. And I would like to do all those things because I quite enjoy doing all those things really. But now I can't really do anything. It is psychological as well. I suppose once you've crossed that barrier, which I think will take a long, long time…"

Wally seemed reluctant to just accept the new way of life associated with the device and was thinking of ways to preserve what things were like before, even though they both knew that it seemed unlikely:

Wally: *"Have a change and say, right, put the bottle in the car, I want to go and drive my car, and see if she can drive her car. If she can drive her car, that's one step. Whether she ever will or not I don't know."*

Wilma: *"I want to, I really want to, that's why I won't get rid of it yet because you never know. Miracles might happen. Don't think so but you never know. It's just – your whole life has gone, hasn't it, really?"*

Wally: *"She is dependent on me and until she can sort of say, 'Right, I'm going to get in my car, I'm going to drive down to my sons and I'm going to do this and do that,' I can't see any change at the moment."*

The fact that neither of them had explained the situation fully to their families signifies a certain amount of reticence and that they were clinging on to the idea that things might revert back in the future so there was no reason to worry other family members needlessly:

Wally: *". . . I don't think I've really spoken to her and said, '[my wife] has got to have this on for the rest of her life.' I*

don't know. I don't know whether I would like to say that just yet just in case something changes."

Wilma: *"Yeah. I haven't said it to mine that it's most probably a permanent, but they know that I can't go anywhere at the minute, that I'm kind of house bound and I can't drive or I won't drive, and I don't want to take that out . . . I just can't put myself through that at the minute. I just want to accept it, I suppose, before anything else . . . It's a big thing really, isn't it? I think it is. If I can't really accept it yet you can't expect them to. Just have to wait and see."*

This sub-theme has described the differences in how couples cope and adjust to life with an oxygen concentrator. Ray and Rita are at different stages of adjusting to their situation. Ray is happy and content with his device and it just fits in with his life. Rita, however, is still struggling to cope and engaging in emotional coping strategies such as wishful thinking about going on holiday and the potential benefits that device use may have on her husband.

Stan and Sally appear in similar stages of adjusting to their situation with both focusing on the positive aspects of the device. Wilma and Wally are also, as a couple, at a similar stage of their adjustment. However, they are still struggling to engage in successful, positive coping strategies and are still selectively attending to how things used to be, wishfully thinking or hoping things may return to how they were before.

6.6.1.4 Along the path to acceptance

Rita and Ray's final interview was conducted earlier than expected (7 weeks after the 2nd interview) because the device had been removed from their home. The device was removed as a result of a follow-up assessment at the oxygen clinic which revealed that there was no longer a clinical need for the device (it was thought that the blood gas results that were obtained when the decision to

initiate LTOT may have been unreliable due to a possible chest infection). The decision to remove the device was made by the oxygen clinic alone. The couple were keen to participate in a final interview following this change of circumstances which provided a valuable insight in to how accepted the device had become.

The device seemed to have become embedded and part of the routine of the users' life. Even after the device had been removed he still looked to use his oxygen in the mornings:

> ***Rita:*** *"The first two days he kept saying, "I'll go and put my gas on". (Laughter) [He] kept trying to put his gas on."*
>
> ***Ray:*** *"Aye . . . It fitted in a pattern. It did."*
>
> ***Rita:*** *"He'd got a pattern on it. He had really become to get a bit of a pattern on."*

This feeling wasn't shared by the partner. As in the previous interview she still hadn't accepted the device fully. This was not necessarily down to a conscious resistance, in fact she fully expected it to become part of their lives and seemed disappointed that it had not, however, she needed more time for this process to become complete:

> ***Rita:*** *"He didn't really have it long enough for me to, though . . . I don't know. As I say, we didn't have it long enough for it to become part of us . . . Because I mean, as I said, I mean I know people who have had them for years and its part of your life, isn't it? I thought that were going to be part of our life . . . And it hasn't, it hasn't worked out."*

The disappointment she felt was mainly due to the feeling of losing all the benefits that the oxygen therapy was providing. For her partner the removal of the device felt like going 'back to square one' or starting again:

Rita: *". . . he was able to sustain being awake a lot longer. Now we're back to he's always asleep."*

Ray: *"Oh aye, yeah. Dozing off again."*

Rita: *"That, he didn't go to sleep when he'd got it . . . You're regressing back again now."*

Ray: *"It's took a week or two, hasn't it, but I have noticed that if you were there, you'd gone five minutes, and you'd come back, you'd bring me a cup of tea, ten minutes later you come back and it's still there, isn't it?"*

Rita: *". . . and his memory was so much better, that's another thing. His memory totally, I could say, I could say what we're doing . . . You know? But you had got so much better than that . . . And you seemed to slip back."*

For both participants the removal of the device seemed to be quite a dramatic event. Instead of being happy that Ray no longer needed to use the device any more, the idea that the concentrator was 'snatched' away implies that it was somehow stolen from them and they were now being left to cope on their own. This suggests, not only a sense of ownership, but that the device was valued by them both:

Rita: *"So when we went again and they reassessed it, they decided that, well to take it off him and for three months we could keep the cylinder . . . And they came in in two days and took it."*

Ray*: "At the end of the day it's what they want to do."*

Rita: *"This bloke come knocking on the door."*

Ray: *"Whatever they want to do. That's right, you're going."*

Rita: *"Then we've got to just [manage]."*

Ray: *". . . They snatch it back."*

For Sally and Stan the journey of acceptance was a lot easier and the final interview illustrated how the presence of the device has been normalised and exists in the background of their lives:

Sally: *"Yeah it seems like it's about three month ago, yeah. Pretty much the same, I mean I've got used to it, it's become part of the norm now and I can't do without it . . . As I say it just all sort of fits into your life and it just becomes normal."*

Stan: *". . . [The concentrator is] not too noisy, get use to that and that just becomes background noise after a while, you don't even hear it."*

Sally: *"I don't even know it's on half the time."*

Stan: *"No, you don't."*

Sally: *"It's like a clock in a room, you know it ticks but you just get used to it, you don't realise it's there."*

Stan: *"You automatically just switch it off."*

However, the initial excitement of finally being given an oxygen concentrator and the comparative ease of transition in to their lives may have masked some of the frustrations associated with the device. Once the novelty had worn off, some irritations became harder to ignore:

Sally: *". . . it is starting to frustrate me because of this everywhere, I get it stuck under doors and wrapped round things, and then I could be walking across the floor and all of a sudden dogs will stamp on it and I'm stuck . . . It was*

all a new thing, you know, and it was exciting and new and now it's like become part of the norm and you start picking on things."

In their final interview Wally and Wilma, who seemed to have the most difficult transition towards accepting the device in to their lives, seemed to have adopted it as part of the family:

Wally: *"The thing is, with the machine I don't even notice it's there now, it's just part of the family."*

Wilma: *"It's like having a dog! . . . You don't really notice it that much now though, do you?"*

Wally: *"I don't notice it at all . . . [at night]I feel with my feet to feel the pipes."*

Wilma: *"It's funny, I think even in your subconscious you know it's there, don't you? It's just… I don't know. I suppose like having a dog, really, you're not going to trip over the dog."*

The likening of the medical device to a pet is interesting as it implies a kind of domestication of 'the medical' into 'the familial'. This resonates with Berker et al, (2005) who have applied this metaphor to situations where users are confronted with new technologies that need to be 'house-trained' i.e. integrated into environmental. So instead of a big, grey medical device being conspicuous within the home, the device is seen as belonging and being part of its surroundings.

The device had become so much part of the background of their lives that ironically now it was the absence of the device noise that signalled its presence:

Wilma: *"No, it's funny, it's just there. When it goes off, like when I go out with a bottle and we turn it off for a little while, it is like the sound of silence, isn't it? You think…"*

Wally: *"Yeah."*

Wilma: *"When it's off, yeah. You kind of think, 'Oh, isn't it quiet?' It's really weird, isn't it?"*

Wally: *"Yeah."*

Wilma: *"Whereas before when we first had it we used to think, 'Isn't it noisy.' So you do – your mind changes, actually . . . It's really weird. That's life."*

This sub-theme demonstrates that adjustment and coping unfolds over time and is multi-directional (Berg & Upchurch, 2007). Sally and Stan who initially found adjusting to life with the device relatively easy discovered that over time different aspects of the device were less than ideal and would require further adaption. In contrast, Wilma and Wally, who initially adopted potentially maladaptive avoidance or emotional oriented coping strategies, found that over time the device has become integrated into their lives.

The previous super-ordinate theme has described a journey or transition that the participants undertook as they came to accept the device in to their lives. The following four themes describe some of the issues that had to be negotiated as they learned to accept life with an oxygen concentrator. These issues are encapsulated in the themes 'making space in their lives', 'negotiating new freedoms/restrictions', and 'negotiating changing relationships'.

6.6.2 Making space in their lives

This super-ordinate theme describes some of the adjustments that participants had to make in order to accommodate the device into their lives and homes. There were two distinct areas in which this needed to take place. The first was the physical positioning of the device in the house, and the second was the time that was expected to be required to use the device.

6.6.2.1 Making room

The position of the device in the home is very important and is determined by different factors such as not being near a source of ignition and being plugged into a fixed electricity socket (as opposed to an extension cable). The device also has to be accessible to turn on and off.

For couple 3 trying to organise their homes to find a place for the device caused some emotional distress. They could not see how the device would fit into their home without causing serious disruption:

> ***Terry:*** *"You can't put a thing in her bedroom."*
>
> ***Tracy:*** *"There's a little bedside cabinet. I can hardly open the wardrobe door onto that. Across the front here there's a radiator and then there's a set of cabinets that are set in. You can't move them. Or this side, apart from a gap behind the door. So you're going to have all that. I just don't know how they're going to do it."*
>
> ***Terry:*** *". . . Where that chair is, it won't take up any more room than that chair."*
>
> ***Tracy:*** *"You wouldn't be able to get through that door then."*
>
> ***Terry:*** *"You would."*
>
> ***Tracy:*** *"You wouldn't. I'm on about having the wheelchair. There's no-way you'd get that door back on here if you put that there. No you wouldn't, impossible. But you'll see anyway, yourself."*

The people who deliver the device have the experience and expertise to suggest where would be best for the device and that is where it is initially placed:

> ***Rita:*** *". . . I thought we were having it upstairs. I'd actually made the space in the bedroom . . . but when the man delivered it, very helpful, very, explained everything, he was brilliant. But he said he didn't think it ought to go upstairs because . . . "If in the day it'd mean you running and down stairs, to flick it on and off" . . . So he advised us to have it downstairs, so that's why I hadn't got anything [organised]."*

Following delivery and initial installation there begins a process of trying the device in different places and moving things around to find the most suitable place for the device in order to minimise disruption. Sitting on different seats or in different places in the room can be as disrupting for people as changing furniture around. For this couple a temporary solution was found and the device was placed in the fireplace, although this would only be acceptable until the fire needed to be put on:

> ***Rita:*** *". . . [And the installer] said, "Put [the device] behind the chair". You can't put it behind the chair because he can't, you have to [move] the chair every time you want to switch it on and off . . . So, we had it there, but [he] weren't comfortable sitting here . . . so we've had to rearrange everything because my fire used to be here and that . . . But my son came and moved it, and we bought wire round, it's still just independently plugged there, so at the moment that's the best place, but come winter it won't be because we have the fire on so I'll have to rethink that one."*

For another couple making room for the device was determined by the level of noise made by the device. The device was moved further and further away from the main living area until a cupboard was cleared out and the device was put in there:

Wilma: *"It was the noise, yeah, but now I can't see it. Before it was at the back of this chair and I would sit here so that was that, it had to go. And then it was over in that corner there and we could still hear it, couldn't we, so it had to go . . . So even the [installer] put it in that cupboard and that's where it has been ever since, in that cupboard. But he said it's alright in there anyway otherwise it would have had to have come out."*

For couple 2 who were looking forward to having the device and were more informed about what this entailed found they had a definite plan as to how the device would fit in to the house and that only a minor adjustment was needed to make room for concentrator:

Sally: *"Well, in my mind I'd thought, you know, it's going to be in the front room, because they did say that I would get plenty of pipe and it would take me round the house, so I wasn't worried about that . . . And I thought well, it's going to be in my front room because it's no good having it upstairs because I'm only upstairs at night, so I'd got it in my mind it was going to be in here. At first it started here, but then I hadn't quite got enough piping, so I've put it in the middle so that it's, kind of, half-way."*

Stan: *"It was a bit short for going up into the bathroom, wasn't it?"*

Sally: *"Yeah."*

Stan: *"So she thought I'll stick it in the middle and get that bit extra length."*

Three of the couples described difficulties associated with finding the right place for the device in the home and that this impacted upon the physical environment aspect of home as described in the working model proposed in chapter two

(section 2.2.2). In particular it interfered with the spatial properties within the home and the activities that those spaces allow. Both Wilma and Rita reported that the device being located in the lounge led to problems, specifically with regards to relaxing and watching TV.

6.6.2.2 Making time

For couples 2 and 4 making time in their lives to use the device was less of a problem as the worsening of their COPD necessitated using the device 24 hours a day. This increased usage was gradually accommodated into their routines:

> ***Sally:*** *". . . At first it wasn't too bad because, as I say, I was breathless but it wasn't too bad. All I know is that I couldn't walk far without getting breathless, and it's just progressed from there and just gradually got worse. So it has had quite an impact on my life, because I'm at the state now that I can't do anything without oxygen . . . I've got to that state when I can't do without it. If I walk from here to the kitchen I'm shattered."*

> ***Wilma:*** *"Well, when I was first on it I was only doing the fifteen hours at night time and I- . . . And I could come down, I could turn it off, and most of the day – I would be breathless but I could manage. I could still cook, couldn't I? Still… don't know if I went to the shops or not. I don't think I've driven since I've been out of hospital. I could still do things at home like cook, wash up, stuff like that. But then it's just progressively got worse and worse and worse and now I just feel as though I can't do anything [without the oxygen]."*

For the remaining couples achieving the recommended 15 hours a day of use proved to be much more problematic. It had been suggested to them that the bulk of this time could be completed during the night while in bed. This in itself

was difficult for the user in couple 1 as he could not keep the tubing on as he was a very restless sleeper. This resulted in trying to accrue time during the day:

> ***Ray:*** *"I take it in there and have my dinner with it."*
>
> ***Rita:*** *"Yeah."*
>
> ***Ray:*** *"It's all time."*
>
> ***Rita:*** *"Yeah."*
>
> ***Ray:*** *"It's adding it on looking for it. Nine hours or something."*
>
> ***Rita:*** *"15 [hours] Supposed to be having it, a bit impossible at the moment."*
>
> ***Ray:*** *"Well it's all adding hours on, isn't it? . . . If I switched it on, [while I have my dinner] that's another two hours, isn't it? Hour and a half, two hours added to. Every day!"*

For couple 3 the idea of having to use the device for 15 hours a day was somewhat unexpected and unwelcome and only added to the sense of fear experienced by the user. The partner, however, seemed supportive and could see how it could be managed on a daily basis:

> ***Tracy:*** *". . . I didn't want 15 hours, I never have done . . . Nobody told me that I'd be on 15 hours or anything."*
>
> ***Terry:*** *". . . Well, it's a big thing. 15 hours seems like a lot of time to me, but since [the nurse] was talking about it, thinking about it, you spend 7 hours in bed and then you come in here and you can watch a programme or a soap or whatever for a couple of hours and it's not long before your 15 hours are gone. So she seems to think it could be better*

that way. I was thinking – 15 hours – you'll never get anything done! Spend all that time …"

Tracy: *". . . Well, don't get me wrong, I wouldn't back out on it. I'd try it but I am still frightened and it's going to take some getting used to."*

Making time is linked to the aspect of home related to promoting a sense of control. The length of time required to be on the device restricts users' ability to control other aspects of their lives and also impacted on the following theme 'negotiating new freedoms/restrictions'.

6.6.3 Negotiating new freedoms/restrictions

COPD is a condition that can severely restrict the mobility of sufferers without increased levels of exertion. The couples in this study describe some of the ways the device impacted both positively and negatively on their freedom.

For Ray and Rita the device acted as both a liberator and a limiter. For Ray, the device acted as an anchor as he did not like moving around too much while connected to it and would much rather be sat down near the device:

Ray: *"Well I tried it, you know, I just put on and you can walk in there provided you watch where [you're going] . . . But I mean, as I say, I wouldn't go wandering anywhere about with it and I just said, if you wanted you could walk in there and come back to fetch anything . . . You know? And I mean. I'd come back, sit down again and that's it. Once you're sat down that's it, isn't it? It's a good thing, got to be."*

Rita, however, expressed a sense of liberation in that the device provided a sense of security for her. It was as if when Ray was on the device he was safe and that allowed her to go out on her own without worrying about him:

Rita: *". . . I'm quite happy to leave him and go out with him on it. Actually I'll, I prefer to, you know, he'll put it on while I go out . . . I'm confident that he's, you're not going to be [doing] nothing silly . . ."*

Couple 2 found the device provided freedom both inside and outside the house. Using the device in the house freed the user from the limitations of being weighed down by heavy oxygen cylinders:

Sally: *"Yeah, I've got loads of this [piping], I could take it all round the house. That was the purpose of it, so that I haven't got to carry my portable oxygen around, because that's heavy to carry round. When I was cleaning round the house I used to have to have that on my back, and it weighs heavy, but with this it gives you freedom to walk all around and you haven't got to carry it round."*

This freedom even extended to taking the device away on holiday. While it was not the easiest thing to move around and it limited the room available in their camper van, it did allow the couple to get away together and not be restricted to staying at home:

Sally: *". . . I mean putting all that lot on the camper; it doesn't give you a lot of space."*

Stan: *"It stays in the front cab."*

Sally: *"It goes between seats."*

Stan: *"We just leave it there switched on."*

Sally: *"So that I can walk up and down the camper and get outside with it as well."*

Stan: *"Yeah. So it has been good for that as well, but it's just the thought… I just felt bad because he's got to lift it*

and carry it from here to the camper which is parked at the back down there. It's not exactly light."

The thought of being attached to the device was a particular problem for Tracy. Her fear of having to use the oxygen concentrator was fuelled by her terror of being stuck in the house and her need for the company of others. This need was reported as manifesting in some potentially risky behaviour such as going out late at night:

Tracy: *". . . I make sure that I get out every day because if I didn't it would drive me up the wall because I'd never see anybody apart from my husband and my son . . . I'm terrified of being stuck in here. I always have done and there's some nights I've got to get out. I don't know why, it's just something. I know this has come about since my daughter died."*

Terry: *"What we do is get in the car and drive around at night."*

Tracy: *"Or I go to Asda and I walk around Asda. I'm going with the dog now on my scooter at night time and I have a walk around, go around with the scooter."*

Terry: *"About 10 o'clock last night, she were on the scooter and I had the dog and go around."*

The presence of the device had reduced their social circle and led to feelings of isolation as their son [a smoker] had told them that he would not visit anymore if he couldn't smoke in the house:

Tracy: *"Our son . . ."*

Terry: *"He pops in . . ."*

Tracy: *"The only thing he'll turn round and say is, well I'm not coming down any more if I can't smoke."*

Int: *"Right, does he smoke in the house?"*

Tracy: *"Yes and he thinks he ought to do."*

Terry: *"We kept telling him to go outside."*

Tracy: *"He says the weather . . ."*

Terry: *"So he says he shan't come any more. So that's it then."*

The greatest restrictions faced as a result of the device were experienced by couple 4. From previously leading relatively independent lives, the device quickly became a central part of both their lives. While the user (Wilma) is physically attached to the device, Wally is, in his own way, also attached to and restricted by the device because he is needed to organise the piping and turn the machine up or down as appropriate:

Wally: *"The worst thing about it is that, at the moment, I can't see any change. She's got to have it on all the time. It wouldn't be so bad if she could take it off for a few hours and go up the garden and do things."*

Wally: *". . . We can't do nothing apart from do the chores around the house . . . Watching when [Wilma] goes up to the toilet and things."*

Wilma: *"It's restricted your life."*

Wally: *"I wouldn't know what would happen if I was working. I'd have to pack in work, at the moment anyway."*

The device was also seen as a barrier to visiting their family. Even though the oxygen company provide a holiday service whereby they will deliver an oxygen concentrator for use away from the home, this user felt that this would be too big an inconvenience for the people they would be visiting:

> ***Wally:*** *"They do say that you can get this machine delivered to wherever you want to go. If she wanted to go and see her sons it can be delivered down there. But they are both working and somebody has got to be there for this thing to be delivered."*

> ***Wilma:*** *"They've both got dogs . . . They've got kids. So, I mean, it's alright with us two because we can put it where we want, that, but with kids and dogs what can you do? They've got to live their life. They can't be rotating around me. I mean, I know they wouldn't mind and that but then I've got to worry about a dog chewing the lead and things like that. There's all these things you've got to take into consideration which we don't have to because we are here on our own. And you can do – well, he does everything now anyway. But going down there, I can't stop the kids from throwing their school bag on the floor and things like that and going out – not going out to play but… they live their life; they need to live their life. Like the dog, she is so used to having the run of the house and things like that; she is a good dog. But you just cannot stop their lives for you, if you know what I mean. They both have to work, both their wives work, so what are you going to do?"*

This theme describes how the device impacts on the aspect of home as a place to go from and return to. For Rita and Ray the device facilitated each of their needs differently. While Ray was happy to use the device as a reason to stay at home, it gave Rita the chance to leave the home without feeling guilty. For Sally and Stan

it has made it easier for them to go on holiday for a short while by taking the device with them. However, for Tracey and Terry, and Wally and Wilma the device has taken away this aspect of the home. Both the device users and their partners have less freedom to leave the home environment. This lack of personal freedom is more associated with environments not considered to be homes (Smith, 1994).

6.6.4 Negotiating changing relationships

6.6.4.1 Conflict/harmony

Accepting the oxygen concentrator into their lives involved the participants having to negotiate changes in their relationships with one another as well as with the people around them. The device was found to be both a source of conflict and of harmony.

On the whole for couple 1 the device was found to help reduce tensions between them. A result of using the oxygen concentrator was that the user was more awake during the day which had been a particular area of tension between the couple:

> ***Int:*** *"So with him, with you being awake a bit more during the day and stuff like that, how did that impact on your lives?"*
>
> ***Rita:*** *"Well lovely because I don't get so frustrated . . . It's very frustrating. I sit hours, you know, and you get no sense out of him, and I'll have a look round and he's gone again, I think, oh . . . Or I'd shout him when I'm in there to look at something on the computer. [With the concentrator] I didn't get so frantic. I admit, I get frustrated then I get nasty with him."*

When the concentrator had been removed thing seemed to have reverted back to how they were before:

Rita diary entry: *"[The user] back to his sleepy self, which had improved with oxygen. [His] sleepiness has got worse, causes a lot of arguments."*

For couple 2 there were aspects of the device that caused a certain amount of conflict. Maintaining the device entails changing a filter at the back of the concentrator, a task that the partner (Stan) did every week. While this is not a particularly big job it was obviously a contentious issue:

Stan: *"It is because I know for a fact she won't change it!"*

Sally: *"I would, if I thought about it!"*

Stan: *"She would wait until it got real solid with dust."*

Sally: *"No, you are making out I am a dirty minger!"*

Stan: *"She will say there is something wrong with my oxygen, I am not getting enough. And it will be the filter!"*

Another area of device use that caused arguments was around the dangers of using the oxygen in the kitchen:

Sally: *". . . a couple of times I have mistakenly gone in there and think oh no I have got my mask on! Take it off . . ."*

Stan: *"She has had enough warnings and bollockings about going in there with it."*

Sally: *"And sometimes I just walk in and forget!"*

Stan: *"You walk in one day with that on, the gas is on, I said there will be an almighty bang and I shall be kissing your arse goodbye. There will be nothing left of the house."*

While not directly related to the device itself, couple 4's area of tension was related to the partner's (Wally) extra responsibilities associated with helping with the piping and extra jobs around the house:

> ***Wally:*** *"We do get a bit trite with one another, now and again."*
>
> ***Wilma:*** *"Tetchy."*
>
> ***Int:*** *"Over the device?"*
>
> ***Wally:*** *"Well yes, over different things. You know she is telling me to do something, I know that I have got to do it, oh alright I am just going to do it, I am going to do it!"*
>
> ***Wally:*** *"What were you shouting to me this morning? It has got jammed . . . Jammed, then I have got to ... I sort of had a minute where I hadn't thought right."*
>
> ***Wilma:*** *"You thought you had got rid or her for a … didn't you? You had got rid of her for a few minutes, having a shower."*
>
> ***Wally:*** *"I do get a bit uptight sometimes, and I think oh I am just going to do the washing up, and I am going to do this, I am going to do that."*

This theme illustrates how the oxygen concentrator both nurtured and threatened the aspect of home as a place to foster relationships. For Ray and Rita life before the device was one where Rita was frustrated much of the time which would often lead to arguments. The effect of the device was to bring the couple together. The effect was reversed when the device was removed from the couple's home. For two other couples, however, the device actually created tension in the relationships. Throughout the literature on home there has been recognition of the importance of how relationships with other people can

contribute towards a place being home (Sixsmith, 1986). So for Stan and Sally, and Wilma and Wally the device may have detracted from their experience of home, especially for Stan whose sensitivity as to the dangers of oxygen use may have led to him feeling less safe in his own home.

6.6.4.2 Increasing physical burden

The arrival of the device into the homes of these participants was not without consequences for the partners in terms of added physical tasks. These tasks increased the burden placed on the partners. For example, for couple 1, the user (Ray) passed on complete responsibility for the device and how it was going to be used to his partner. She went away shortly after the device was delivered so very little had been arranged as he was waiting for her to get back and make all the decisions:

> ***Ray:*** *"Once the wife gets here we'll get it, probably get it upstairs and she'll find a way of fastening it down . . . Once she gets back it's sorted, she's back on Sunday."*

Ray was not even going to read the information folder that came with the device and was going to leave that for Rita to sort out:

> ***Ray:*** *"There was that, there's a big folder . . . Yeah. Orange file. I've not opened it . . . No, she'll read it, she'll read it through, won't she? Ah. And she'll tell me all about it."*

As described previously the partner in couple 2 took on the role of cleaning the filter which could, at times, be a source of tension. Since the device has been delivered he had also had to take on responsibility for vacuuming every day:

> ***Sally:*** *"Yeah. He does the hoovering because the machine's heavy. Even with this on it's quite heavy to push around, and I just do all the dusting and polishing, but he does the vacuuming every day, which has to be done because we've got two dogs . . . It was, like, just occasionally he used to do*

the vacuuming for me but now he does it every day because he knows I can't do it. Even when I'm cleaning the house now with this on it's a case of do a bit, stop, do a bit, stop. I can't just plough through it."

The increased physical burden for couple 4 was quite profound. The role of partner became subsumed by the role of carer; a change in role that was acknowledged by both of them:

Wally: *"Yeah. Whereas the woman in the house would probably do the chores and that, I could be out working in the garden or on the car, whereas I can't do that now. I have to do the chores; hovering, shopping, everything. So I am a carer overnight . . . All this cable, I have to be here to turn it up and turn it down, when she goes up the stairs, then when she goes I make sure all the cables are here so they don't get tangled up, and -because we have got a stair lift now . . . Well, you know, I am not as young as I used to be."*

Wilma: *"That is a lot of the trouble, isn't it?"*

Wally: *"Yeah, oh yeah. Every time Wilma goes up the stairs I have to get all that tubing and… especially at night when she is going to bed, I have to tuck it in a certain place, don't I, make sure that she's got enough in the bedroom."*

Wilma: *"Yeah. It is hard work. Blinking hard work. See, now he likes – reduced to doing the dinner as well, aren't you? I can tell him what we're going to have or…"*

Wally: *"I'm a cook as well now."*

Wilma: *"Chief cook and bottle washer, aren't you? . . . Oh dear."*

Wally: *"Life has changed."*

While Wally has other chores around the house, he is needed to attend to the piping when it gets stuck as Wilma moves around the home and this demonstrates how Wally is himself also connected to the concentrator. It seems as if his own freedom is curtailed by the device because Wilma's freedom to roam is reliant on him being available to free the piping. It is unclear whether such innocuous terms such as 'bit trite', 'tetchy' and 'uptight' fully represent how they feel or were used to down play the situation due to interviewing both patient and partner together.

6.6.4.1 Increasing emotional burden

As well as a physical burden, the oxygen concentrator provoked an increase in the emotional burden experienced by the partners of the users. For couples 1 and 2 the device seemed to put a lot of focus on the user, which meant that the partners received less attention and in some way felt forgotten about. The partners each had their own life events which had become marginalised since the device had entered their lives:

Rita diary entry: *"Felt a bit selfish after [the researcher] visited saying I wasn't keen on fact that machine stopped me from moving furniture around. At the moment everything centres around [the user] and oxygen."*

The partner in couple 1 reported a fall that she had suffered but felt that regardless of her own condition, her husband's need were more important:

Rita: *"I fell three weeks ago, on the, I tripped on the stair . . . Scars, I've got, terrible. And I'm thinking, and there then I'm thinking, "I can't go to hospital". I sat on the [step] and I thought, 'I can't because who's going to look after him?' .*

. . 'But it's not about me, it's about him. Life's about [him]'.

Similarly the partner in couple 2 had his own health problems. While the interviews were obviously centred on the device, the partner would talk at length about his own health problems whenever the opportunity arose, going into great detail. It was as if it was a way for him to be able to express his own importance:

Stan: *"Yes. So I have been back in since I last saw you . . . Yes, the doctor gave me a bollocking . . . Only the other month of being in and out of [hospital], 6 times. The PCT is playing up, the trust is playing up, nobody knew what was going on. So because I am on Oramorph, and I am taking that, I have been on that for quite a long time now, it has got to the point where I am told to take it until the pain goes . . ."*

Stan: *"Well, I came out of hospital, had my operation, had problems on recovery, had a bleed into the heart which wouldn't stop for a minute . . . I was on a different pain killer, which is class A and I had another class 'A' I picked up from the chemist which I shouldn't have done."*

The emotional burden for the partner in couple 4 was quite different. Firstly, the speed of her decline in health and associated low moods were something that, due to their social isolation, he alone was witness to. He was required to provide the support she needed to get through the bleak periods:

Wally: *"I certainly do worry about it as well because seeing [her] go down so quick it does worry you."*

Wilma: *"How long I've got left."*

> ***Wally:*** *"Sometimes really she has her dark times when nobody is here, nobody else sees the bad times apart from me. Just got to fight on."*

Adding to his worries about his wife was the fact that using the device could be dangerous, which seemed to make him more sensitive to quite normal situations:

> ***Wally:*** *"It worries you sometimes, because they do say that if you fall asleep, or in the daytime or anything else, the first sign is the carbon dioxide building up, making you drowsy, and when she oversleeps sometimes, I get a bit worried, because I think maybe something is not right."*

The home appears as a profound central emotional and sometimes physical reference point in a person's life which is encapsulated in emotions which include happiness (Sixsmith, 1986). While the device users receive a physical benefit from using this equipment, for their partners having this particular medical device in the home does little to foster a sense of happiness or emotional security.

6.7 Discussion

The aim of this study was to describe the experience of being provided with an oxygen concentrator to use in the home from the perspective of both the user and their partner. This study illustrates that there is a process to go through with regards to adjusting to having an oxygen concentrator in the home and the different issues that have to be negotiated as couples adjust to their changing lives over time.

The super-ordinate theme 'adjusting to a new life' described how the couples moved through the process of adapting to having the device in their lives.

Adjustment can be defined as a series of small changes in a person's usual behaviour in order to meet life's problems more effectively (Keogh et al., 1999).

Coping is a factor repeatedly implicated as influencing adjustment to chronic illness and how an individual copes with his/her illness has been repeatedly linked to psychological adjustment outcomes (Walker et al., 2004). The cognitive-appraisal model of coping proposed by Lazarus and Folkman (1984) refers to the continually changing cognitive and behavioural efforts to master, reduce or tolerate the internal and/or external demands that are created by a stressful situation.

As noted in the literature review, emotion-focused or avoidance-oriented coping strategies are more likely to result in maladjustment to chronic diseases over time (Covic et al. 2003; Dew et al., 1994) while, approach or active-oriented strategies appear to be more effective in the adjustment to long-term illness (Keefe et al. 2002; Young 1992).

This study has described the coping strategies utilised by couples as they adjust to the introduction of an oxygen concentrator into the home environment. Participants who were least prepared for life with the medical device appeared to initially adopt more avoidant coping strategies compared to the couple who appeared more prepared for the change in circumstance who utilised a more active coping strategy. However, by the final interview, regardless of which coping strategy was used, couples appeared to have similarly adjusted to life with the concentrator. In fact, over time, the couple that engaged in an active coping strategy by using prior knowledge and visualising a favourable outcome identified new device-related stressors.

This is notable because a consistent finding of the health related coping literature is that avoidant coping strategies, such as distancing and denial, have been associated with poor adjustment to chronic disease in individuals who are contending with a variety of different stressors (e.g. Carver et al., 1993; Christensen, 2000; McCathie et al., 2002). Emotion-focused or avoidance-oriented coping only had a detrimental effect in the present study when couples were first given the device, which suggests that coping with the introduction of

an oxygen concentrator in the home environment has unique characteristics that distinguish it from coping with chronic illness in general.

The chronic nature of COPD is predictable and deteriorations in symptoms generally only change markedly over a relatively long period of time - several months or years (DoH, 2011). The prescription of an oxygen concentrator, however, introduces uncertainty into patients' lives. Uncertainty in illness is defined as the inability to determine the meaning of illness-related events, assign definite values to objects and events, and/or accurately predict outcomes (Mishel & Braden, 1988). Short-term uncertainty is associated with acute, rather than chronic illness, and is associated with greater use of emotion/avoidance coping (Mishel, 1997; Neville, 2003). The findings of this study suggest that couples who did not know what to expect with regards to the oxygen concentrator in this study experienced more short-term uncertainty and engaged in coping that involved rejection and denial. The couple with a greater understanding and realistic expectations regarding the device were less uncertain and adopted more appropriate positive visualisation and planning.

The ease with which these couples adjusted to life with the oxygen concentrator appeared to be mediated by the expectations that they had about the device. Patient expectations are seen as exerting an important influence on healthcare experience and satisfaction and that information given to patients can help manage and modify those expectations (Conway and Willcocks, 1997) and play an important role in the acceptance process (LaChapelle et al., 2008).

The role of patient education has been discussed widely within different medical specialities and in relation to different types of medical devices. Multifaceted education has been aimed at facilitating the choice of dialysis treatment for patients with chronic kidney disease (Manns et al, 2005). Patient education for people with chronic obstructive pulmonary disease has been identified as being particularly significant (Curtis, et al., 2002) and is considered an important issue for future research in COPD (Croxton, & Bailey, 2006). It has also been proposed that comprehensive education resources for patients, families, caregivers and

the public be developed in different media in order to enhance quality of care (Doherty & Petty, 2006).

Patient education in relation to LTOT in the UK is mainly concerned with practicalities, safety and encouraging treatment adherence, although the importance of the spouse/carer attending the session is also stressed (British Thoracic Society, 2006). The content and level of patient education provided to the participants in this study is not clear (other than printed material provided during device installation) as the researcher was not present during patient consultations in the clinic. Also as the importance of patient education was not revealed until the transcripts were analysed it was not a explored during the interviews. While all the couples were aware of issues around safety, how to use the device and what was required by way of cleaning the filter, it seems that this information did little to prepare three of the couples for the initiation of therapy and the installation of the oxygen concentrator. The couple that found the transition relatively easier compared to other participants spoke about how the experiences of others had helped her not only prepare for but also look forward to being given the device. The opportunity to find out more about the oxygen concentrator, including information about the benefits and problems that had been encountered by other users, was not available to the other couples.

The importance and benefits of peer education have been discussed with reference to other chronic diseases and devices, for example, percutaneous endoscopic gastrostomy placement (Gunnell et al., 2005) and chronic kidney disease (Morton et al., 2010; Rygh et al., 2012). In order to facilitate acceptance and inform expectations of LTOT, the education of users and partners should occur prior to delivery of the device. This kind of pre-intervention education may provide the patient with a 'dry run' of how they are going to cope when the time comes (Kendall et al., 1979). The practicalities of this may be problematic under the current system. As per the guidelines patients are assessed twice approximately 4 weeks apart in order to ascertain suitability for oxygen therapy. If after the second assessment LTOT is indicated the equipment is delivered to the patient's home within three working days. This, therefore, gives little time

for either the delivery of a comprehensive education package or time for the patient to process the information given to them and make informed decisions about whether to accept the treatment or make preparatory adjustments to the home.

While participants in this study were given information in terms of the practicalities of using an oxygen concentrator (prolonging life, not smoking, time to spend on the device etc.) and the installer of the device provided a file containing other practical information, the emphasis was, not surprisingly, on the positives with little if any mention of the negatives. These finding are similar to Lehoux et al., (2004) who considered that "*While this is not surprising, it remains nonetheless questionable, since patients are 'forced by default' into using a given technology, not knowing all of its benefits, as well as the drawbacks that will structure their entire life."* (p639).

The themes 'making space in their lives' and 'negotiating new freedoms and restrictions' support the findings of the first study discussed in chapter four that medical devices can both facilitate or threaten different aspects of home which affects people's experience of that environment.

In this study the oxygen concentrators had a particular effect on the physical aspect of the home. Because of the size and the noise generated by the device, couples found that they had to rearrange furniture and re-position the device in order for the concentrator to be assimilated into the home environment.

The installation of the oxygen concentrator also entailed couples having to negotiate new freedoms and restrictions. This theme relates to people's experience of control as an aspect of the home environment. The home should be the place where people are most in control and have the power and freedom to make choices and complete desired actions (Sebba & Churchman, 1986; Tanner, 2008). For one couple the device gave them the freedom to leave the house by taking the device with them on holiday. For the other couples the device restricted their ability to leave the house and so they were not free to live life as they desired.

The theme 'negotiating changing relationships' describes the different ways in which the device impacted on the aspect of home as a place to foster relationships.

A number of qualitative research studies have described the relationships between people with COPD and those that care for them. These studies have described the increasing physical and emotional burden placed on partners caring for people with COPD and the tensions that can arise within their relationships (Bergs, 2002; Seamark et al., 2004; Simpson et al., 2010). The present study not only adds to this literature but also describes the ways in which the oxygen concentrator itself contributed to these issues in terms of its effect on different aspects of home.

While for some of the participants the device had a positive impact, for a lot of the time the device added to the partner's physical and emotional burden with regards to looking after the device and in some instances became a source of tension or conflict. This threatens home as a place that encourages the experience of happy events and general feelings of happiness (Sixsmith, 1986) and contributes to a negative atmosphere within the home which is associated with environments not considered to be homes (Smith, 1994).

6.8 Limitations

A small sample size and the homogeneity of the participants in this study was not ideal. Due to recruitment difficulties and the short time between patients' final assessment and the device being delivered it was not possible to interview all couples before the device was delivered. This made it difficult to understand the transition from non-user to user of the medical device. Furthermore, two of the couples (Ray/Rita and Tracy/Terry) had the device removed before the end of the study, which impaired some of the longitudinal aspects of the study. While this was not ideal it did allow for an interesting retrospective insight into how they felt about the device and it does reflect the real world situation of these people.

Device users and their partners were interviewed together for this study. This did facilitate some good discussions and allowed the researcher to see how they reacted to each other but it may have resulted in a less open discussion. It may for instance have been more difficult for the partner to express openly negative feelings or emotions about the device which the user was reliant on for fear of upsetting that person or making them feel guilty.

Another limitation may be that the study was not long enough in duration and that the issues raised may be considered to be a short-term hurdle to overcome. It is also possible that over time other issues may have arisen or become more prevalent.

6.9 Summary and contribution of this research

The aim of this study was to answer the research question:

What is the lived experience of couples who are given a medical device to use at home and how does this change over time?

The previous study described in chapter four demonstrated that medical devices are intrusive and that these devices may impact on the different 'aspects of home' requiring users and partners to make adjustments to the way that they live in their own homes. The present research has extended the understanding of these issues and describes their importance for the necessary coping and adjustment that medical device users are required to make to accommodate an oxygen concentrator into their lives.

As discussed in chapter two, previous work in this area has been cross-sectional in design where the views of a cross-section of home device users were collected at a single point in time to provide a 'snap shot' of common themes or issues (e.g. Fex et al., 2009; Lehoux, 2004). There has, until now, been no longitudinal research that has captured the process of coping and adjusting to issues in relation to the provision of an oxygen concentrator to provide long-term oxygen therapy.

This research has described how, in contrast to the predictable and chronic nature of COPD that couples have learned to cope with, being given an oxygen concentrator is an acute episode of uncertainty for some couples that requires different coping strategies. The ease with which these couples adjusted to life with the oxygen concentrator appeared to be mediated by the expectations that they had about the device. Education may be beneficial in managing patient expectations and should not only concern the practicalities associated with the device, but should also cover the potential psychological and social impact.

This study also supports the findings from the research described in chapter four that demonstrates the ways that medical devices can influence the physical, personal and social aspects of the home environment.

The following chapter will describe an activity where the results of all three studies are presented to different stakeholders in order to validate and obtain feedback on those findings which would help contextualise the findings in relation to current healthcare practice.

Chapter 7: Stakeholder feedback

7.1 Introduction

The three studies described in this thesis have demonstrated that

- Medical devices can either support or threaten people's experience of different aspects of the home environment.
- There is a process of adjustment to living with a medical device in the home environment and that managing people's expectations may reduce the uncertainty associated with this change of circumstance and ease the transition into this new situation.
- The aspects of medical device use associated with compliance with treatments to improve clinical outcomes are ranked as more important by a variety of stakeholders than aspects concerned with device satisfaction.

This chapter describes four stakeholder feedback events. These events aimed to not only disseminate the findings of the studies but also to obtain feedback on those findings which would help contextualise these findings in relation to current healthcare practice.

7.2 Member checking

Meyrick's (2006) framework (described in chapter three) and independent audits were used to assess the rigour or quality of the qualitative studies described in chapters four and six. In order to assess the general acceptance of the research findings and obtain feedback on the findings of the three studies as a whole a different approach was used.

A variety of approaches can be taken to assessing and ensuring research quality and providing external validation of an analysis. These include employing multiple coders, triangulation of data sources, and respondent validation (Blanford, 2013).

Miles and Huberman (1994) emphasise the importance of verifying qualitative findings and focus on the agreement of codes between multiple analysts. Having multiple independent coders of data is particularly appropriate for studies where a predetermined coding system is developed in which code names and meanings have been agreed. It is less useful, however, where the study relies on a rich interpretive analysis (Berends & Johnston, 2005).

Triangulation involves comparing multiple data sources or different methods of gathering data. The researcher looks for patterns of convergence to develop or corroborate an overall interpretation and this can be seen as a way of ensuring comprehensiveness rather than as a pure test of validity. (Mays & Pope, 2000).

Respondent validation or 'stakeholder or member checking' has been described as "the most critical technique for establishing credibility" (Lincoln & Guba, 1985 p 314). Stakeholder checks can enhance the credibility of research by giving participants and other people who may have specific interests in the work the opportunity to comment on or assess the research findings, interpretations, and conclusions (Thomas, 2006). This method is not without its limitations, however; Mays and Pope (2000) highlight that as the account produced by the researcher is designed for a particular audience it will, inevitably, be different from the account of an individual informant simply because of their different roles and priorities in the research process. Moreover, participants may not be in the best position to check the accuracy of accounts as information may have been forgotten or feelings about certain issues may have changed over time (Sandelowski, 1993). As a result, stakeholder checking can be seen as a of process of dealing with discrepancies or confirming instances in the responses of stakeholders that also generates original data, which in turn requires further analysis (Bloor, 1997).

It was decided that stakeholder checking would be the best method to enable dissemination of the findings of this research as well as providing the opportunity to obtain feedback and position those findings in relation to current healthcare practice. It is noted that these events were not designed to validate the findings

of the preceding research in terms of affirming that the findings reflect/conflict with the views, feelings, and experiences of the participants involved. Rather, the mix of stakeholders recruited for these events would be used to demonstrate the general acceptance of the findings and allow identification of contradictory evidence.

7.3 Development of the stakeholder feedback events

While the term 'stakeholder' is predominantly associated with the business sector (Svendsen, 1998), it can easily apply to the healthcare arena using Hatch and Schultz's (2003) definition of stakeholders as including employees, customers, suppliers, regulators as well as people with special interests and local communities.

The stakeholder event used personas and scenarios to present the research results. It was recognised that some of the stakeholders involved in this event may have been unfamiliar with academic research and therefore it was desirable to present the results of the studies in a tangible format. These techniques have been found to be useful in stimulating dialogue and critical reflection on design and the development of ideas with multiple stakeholders (Nilsson & Fältholm, 2011).

Scenario-based techniques are often used in participatory design orientated tasks. Scenarios are stories that have a setting and a plot or sequence of actions and events involving actors or agents who have goals or objectives (Carroll, 2000). Personas can enhance engagement and provide a foundation on which to build a scenario around in order to both disseminate and elicit research data (Grudin & Pruitt, 2002). A persona is a fictional exemplar of a person. To make this persona believable or 'real' it is given a name and a face, and is carefully described in terms of needs, goals and tasks (Blomquist & Arvola, 2002). The personas created for the stakeholder events were not meant to provide a global representation of a particular user group but were designed purely as a way to

support communication and act as a means to aid discussion and dialogue, as described by Vincent and Blandford (2014).

It was decided that applying the findings of the previous studies to a different medical device that had not been investigated in the thesis would help assess the generalisability of the research findings. The device chosen would have to be used in the home and have been shown to have the potential to impact on both the user and the partner. During the interviews conducted in chapter six, two of the couples spoke about the impact the continuous positive airway pressure CPAP device had had on them or people they knew. The literature suggests that this device does indeed impact on partners and users. For example, some partners report moderate to severe sleep disturbance from CPAP machines, (McArdle et al., 2001). Other research has shown that adherence to CPAP in married men is strongly related to the frequency with which their partners sleeps with them during their initial home treatment and that some wives who sleep in a separate bed or room do not return to share the bed even after the sleep disorder is under control (Cartwright, 2008). For these reasons obstructive sleep apnoea and the CPAP medical device were selected as the topic for this stakeholder event and were used to form the basis of the personas and scenario.

Obstructive sleep apnoea (OSA) is a condition where, during sleep, the walls of the throat relax and narrow causing a total blockage of the airway and the interruption of normal breathing for 10 seconds or more. During this time, the lack of oxygen triggers the brain to wake the person out of deep sleep. This then allows the airways to reopen and the resumption of normal breathing. After falling back into deep sleep, further episodes can occur. In severe cases this cycle of interrupted breathing, waking and sleeping may occur around once every one or two minutes (White & Younes, 2012; NHS Choices, 2014).

Night-time symptoms of OSA include loud snoring, laboured breathing and repeated short periods where breathing is interrupted. (Young et al., 2002). Day-time symptoms may include: not feeling refreshed after waking up; day-time sleepiness; road traffic incidents or near misses when driving; poor memory and

concentration; irritability and mood swings, depression and decreased libido (Greenstone & Hack, 2014).

A persona 'Fred' was created who had a diagnosis of both COPD and OSA (OSA often coexists in patients with COPD). The clinical profile of such patients can display lower day-time arterial oxygen levels, higher arterial levels of carbon dioxide and higher blood pressure and an increased mortality risk compared with patients with OSA alone (Weitzenblum & Chaouat, 2004; Lavie et al., 2007).

A widely used treatment for OSA is the delivery of continuous positive airway pressure to the upper airways. The CPAP device (see figure 7.1) consists of a motor unit that pushes filtered air out through a variety of different facial mask (covering just the nose or the nose and mouth) at a positive pressure that is individually adjusted for each patient. This keeps the collapsible upper airway open while the patient continues to breathe (Ho & Brass, 2011). Treatment with CPAP can also improve gas exchange in patients with both OSA and COPD, which is associated with a fall in hospitalization rates (Mansfield & Naughton, 1999).

Figure 7.1 CPAP machine and face mask (source: Heartlands Hospital sleep clinic)

The personas developed for this event were based on the prevalence and progression literature summarised by Young et al., (2002) and the suggested management of sleep apnoea in the UK set out by National Institute for Clinical

Excellence (2015). They consisted of a couple (Fred and Wilma) who were both aged over 65. Wilma is 67 and in relatively good health. Fred is 68 and has stable COPD managed by his GP. Fred has been to his GP at the insistence of his wife due to excessive snoring at night, impaired concentration and generalised fatigue during the day. His GP has referred him to the sleep clinic at the local hospital where he was diagnosed with obstructive sleep apnoea and it is suggested that he be given a CPAP device (see appendix 6 for visual representation of the personas).

Once the persona was completed a 'utopian future' scenario was created, based on an approach developed by Drewes Nielsen (2006). Creating a utopian perspective allows participants to situate themselves in an exaggerated perfect world where everything is possible. This supports creative thinking about the future with the purpose of transforming a current or problematic situation into a preferred one (Gkouskos et al., 2014). This method was chosen as it was thought that by creating a utopian future scenario (based on the findings of the studies in this thesis) stakeholders would be free to consider possible ways to facilitate this future, which would stimulate discussion and contextualise the research findings in relation to current healthcare practice. There is a tendency for utopian views to promote an overly positive, unrealistic and unachievable future situation (Lee & Lee, 2010) and for that reason scenarios need to adhere to three basic principles (Gray & Hovav 1999). They must be:

- 'Possible' (implying that there are no immobile barriers to the events being described, such as defying the laws of physics)
- 'Plausible' (implying that the reader of the scenario would believe that the events could occur)
- 'Internally consistent' (all parts of the scenario are consistent with one another)

The initial stage of constructing the scenario was to map out the personas' journey from pre-diagnosis of the medical condition to receiving the medical device. In order to adhere to the principle of scenario construction, a simplified 'patient journey' was devised based on UK guidelines regarding the diagnosis and

treatment of obstructive sleep apnoea (Scottish Intercollegiate Guidelines Network, 2003). Added to this pathway were interventions or actions, based on the findings from the studies included in this thesis (see table 7.1). This scenario presented a utopian future view of the patient journey that would be used to stimulate discussion and feedback of the research findings when presented to the stakeholders (see appendix 7).

Scenario intervention / Originating study	**The effect on the partner** couples should be considered together	**Managing expectations** Suggested places for further information provided	**Managing expectations** Preparation for future medical decisions	**Managing expectations** Familiarity with medical devices	**Acceptance** Time to adjust to changing situation	**Expectations and acceptance** Opportunity for discussion	**Choice of device** Given choice & option to change
Study 1 Qualitative Interviews (chapter 4)	✓						✓
Study 2 Questionnaire (chapter 5)	✓						✓
Study 3 Longitudinal study (chapter 6)	✓	✓	✓	✓	✓	✓	✓

Table 7.1 Scenario intervention and originating study

7.3 Method

7.3.1 Stakeholders

Ethical approval for this study was granted by The University of Nottingham Faculty of Engineering Research Ethics Committee. Six stakeholders were purposively sampled to represent different professional groups that may be involved in the provision of medical devices that may be used in the home. Purposive sampling techniques are often used in qualitative studies (Teddlie & Yu, 2007) and may be defined as a type of sampling where ‘‘particular settings, persons, or events are deliberately selected for the important information they can provide that cannot be gotten as well from other choices’’ (Maxwell,1997 p. 87). Four of the stakeholders were associated with the oxygen clinic where recruitment took place for the study described in chapter six. This was

particularly useful in providing an opportunity to link research to current practice. One participant was a non-device user aged over 65 who had friends and relatives who were users of medical devices in the home.

The stakeholders were as follows:

- Head of a local respiratory service*
- Consultant physician
- Medical registrar
- Respiratory nurse specialist*
- Respiratory assistant practitioner*
- Respiratory physiotherapist*
- Non-device user aged over 65

* Healthcare professionals who belonged to the oxygen clinic from chapter six.

7.3.2 Procedure

The purpose of the events was to disseminate the findings of the studies conducted as part of this thesis and to enable stakeholders to comment on how these findings resonated with their clinical and personal experience.

All events followed the same format. One event was conducted in a group of four stakeholders and three were one-to-one sessions.

The stakeholder events comprised of five phases (see figure 7.2)

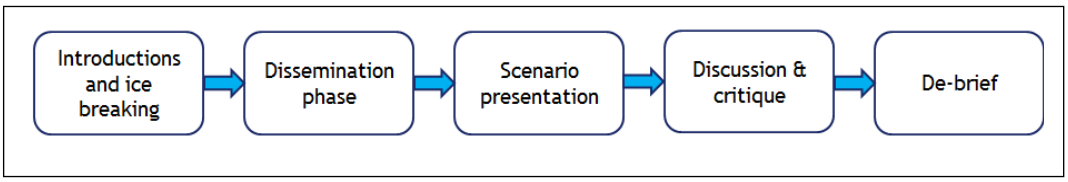

Figure 7.2 Stages of stakeholder event

1. **Introductions and ice breaking phase**

Information was given about how the event would proceed and what was expected from the stakeholders. Stakeholders were asked to complete a consent

form. The researcher and stakeholders were introduced to each other and a small ice breaking task was used to put people at ease and produce an atmosphere conducive to an open discussion.

2. **Dissemination phase**

A presentation was made to the stakeholders that outlined each of the three studies in turn and their findings. The stakeholders were given the opportunity to ask questions and provide general feedback after the presentation of each study. No participant identifiable information was used in the dissemination of the findings. This was particularly important as healthcare professionals from a recruitment centre took part in the events.

3. **Scenario presentation phase**

The personas and scenario were presented to the stakeholders along with the chance to ask questions to further understanding.

4. **Discussion and critique phase**

In this section discussion and critique of the utopian future scenario took place. The strengths of the proposed patient journey were discussed as well as ways in which these changes could be facilitated and how this related to the Stakeholders' understanding of current systems and practice.

5. **De-brief phase**

Stakeholders were asked for feedback on the project as a whole, and what they thought were the overall strengths and weaknesses of the research. They were asked who they thought the results would be useful for and what future research should be conducted in light of the findings. A final chance to ask questions was also presented.

Feedback at each stage was captured in writing on sticky notes either by the stakeholders themselves or by the researcher (see appendix 8).

7.4 Results

The purpose of this work was to use the study presentations and scenario as inputs and stimuli for discussion in order to review the credibility of the findings. Thus this section will consist of reflections from the discussions that arose from the events which will be illustrated with the use of paraphrased quotations from notes generated at the time.

7.4.1 Feedback on study 1

The feedback on study one was generally positive. There was recognition that some of the issues identified in the study had resonance and stakeholders were keen to share anecdotes of their own that chimed with those that they were presented with. The healthcare professionals from the oxygen clinic reported that the work had identified a number of things that they had not known, which they felt was beneficial:

> *". . . we don't get told a lot of things and have never really thought about the impact on the partner"*

This was echoed by the physician who could see the applicability of the findings to the medical devices in her clinical area (infusion pumps for home antibiotic therapy). She also reported that the findings could be important to her practice:

> *"I should imagine that these factors would have an influence on adherence which is very important".*

The medical registrar noted that these factors are important but reported that, as a profession, medicine does little to address these concerns even though there is an increased focus on 'person-centred practice'.

For the healthcare practitioners, this study definitely highlighted issues surrounding the impact medical devices had on the home environment that they had not previously considered. That practitioners were not informed of some of the issues nor had considered the impact on the partner maintains the view of

the home as a private space. This suggests that once devices enter the home environment they become part of that environment and the responsibility of users and cease to be part of the medical world outside the home.

Comments by the physician and the medical registrar supports the premise that at least as far as medical devices are concerned, a more paternalistic approach has been adopted. The use of the term adherence is notable as it is most commonly defined as the “extent to which patients follow the instructions they are given for prescribed treatments” (Haynes et al., 2005 p2) The concept of adherence is referred to in the healthcare professional literature synonymously with the term compliance, which has been criticised for its paternalistic undertone (Christensen, 2004). More recently there has been increasing use of the term concordance, which implies an alliance between patients and healthcare providers, which places patients’ expectations about treatment recommendations as equal to or even more important than healthcare professional’s expectations (Bissonnette, 2008).

7.4.2 Feedback on study 2

Given the results of the first study there was general surprise from all stakeholders that the 'satisfiers' section of characteristics were ranked so low by all groups. In particular, there was an expectation that these characteristics would be ranked higher by the non-medical professionals, which was not the case.

The rankings of those device characteristics in the top part of the table (see table 5.2, section 5.3.1) by the medical professional groups were less surprising to the stakeholders. There was acknowledgement among the healthcare professionals that “I guess we don't think about those things at the bottom of the table” which indicates the novelty of the research findings regarding the impact medical devices have on the home environment. The non-device user also “expected the clinician view of these characteristics to be more pragmatic than that of users or non-users”.

This feedback supports the conclusions of the second study: that the practical device characteristics that may enable use or enhance adherence appear to be the factors that 'must be addressed' and that the factors related to satisfaction would be 'nice to address'.

7.4.3 Feedback on study 3

Hearing detailed results from study three was particularly interesting for the healthcare professionals from the oxygen clinic. They reported that there were substantial advantages of conducting independent research on this topic:

> *"The study has opened our eyes . . . we are getting a real picture . . . because patients don't tell us any of this!"*

There was also surprise that patients didn't know what to expect when being given the medical device as "we give them lots of information".

That lots of information is 'given' and 'patients don't tell' again implies an unequal partnership between healthcare practitioner and patient. There was no reference to practitioners checking patients' understanding of the information that they had been given or that patients were asked about any problems or concerns.

The physician reported that the issues of acceptance and upsetting the routines of patients had not been previously acknowledged and that greater awareness of these concerns was important, especially if they could promote greater adherence. This was echoed by the registrar who admitted that they are just not trained to think about the partner:

> *"All we tend to consider is whether the device will have the desired effect on the condition, we don't consider the psychological effect on the person or how it might affect the partner and the results that you have presented just confirms that we should be".*

Again the doctors' comments support a biomedical approach to medical device use and are likely to be indicative of the medical training that they have received. Interestingly the physician saw acceptance of the medical device and upsetting routines and home environment in terms of promoting treatment adherence as opposed to the potential psychological effect it may have on the user.

According to the non-device user the impact of medical devices in the home was "probably much overlooked . . . and that clinicians need to be responsible for the emotional impact the devices have". This non-device user placed the responsibility for the impact of medical devices firmly in hand of healthcare practitioners. This runs counter to the person centred, share decision making delivery of care for people with chronic diseases proposed by government policy and supports the literature that reports that the extent to which patients want to participate in decisions and share responsibility for treatment may vary according to a number of factors including age, education and social economic status (Krupat et al., 2000; O'Connor et al., 2003).

7.4.4. Feedback on the utopian future scenario

Due to the busy work schedules of the stakeholders it was not always possible to devote significant time to a full discussion around the scenario with most sessions only lasting 10 minutes.

There was a strong feeling that GPs have an important role to pay in managing patient expectations and there is a real opportunity for GPs to be able to signpost patients to places for further information. It was suggested that they could provide information about illness, what to expect at clinics, treatments and support and that the use of digital media (i.e. websites or email) would be the best means of achieving this.

It was recognised however, that in reality GPs could not know everything about all the different clinics and what would happen to patients when they got there. There was some concern about who would be able to set these processes up and

the resources that would be needed to ensure that the information and guidance was kept up to date. This increase in workload would be adding to a service already under exceptional pressure and may have a detrimental effect on the time GP's are able to spend with patients (Rimmer, 2015). Unfortunately there were no GPs represented in the stakeholder groups so it was not possible to ascertain what GPs are currently able to do with regards to managing patient expectations.

Across the whole scenario it was acknowledged that the inclusion of partners in care planning would be beneficial and that healthcare professionals should look at ways in which they may be involved. The stakeholders did note that including partners does raise issues regarding confidentiality and that opportunities to involve partners would have to be handled sensitively to ensure that neither patients nor partners did not feel pressured for partners to be involved.
With regards to the things that the clinic could realistically do to manage the expectations of being given a CPAP device, it was noted that the quality of the information patients are given is more important than the quantity of information given. There were suggestions that the information provided should include more pictures and video. One healthcare professional suggested that a post diagnosis group education similar to ante-natal classes could be a way of engaging with patients and helping them understand what would be involved in being given this particular device.

While clinics provide another opportunity to provide information, it was noted that patients should be able to choose what information they would prefer and in what format. One healthcare professional made the point that you can give as much information as you like but there is no guarantee that people will look at it. It was also noted that as different clinics may operate in slightly different ways that the information given could only be organised at a local rather than a national level.

The suggestion that patients could be given a 'cooling off' period prior to being given a device in which to adjust to their changing situation was met with differing opinions. The nurses were not sure whether this was a good idea, while the physician and the registrar thought it was a good idea as there seemed little point in giving someone a device unless they were totally 'on-board' and going to use the device as directed.

The recommendation that a patient should be given a choice over the type of device they are given was met with general approval and stakeholders reported that this should be actively promoted especially if the device is to be used long-term. One caveat to giving patients a choice of device was that this should be balanced with the cost of that device i.e. that if efficacy and cost are similar between the devices then there is no reason why patients should not be given a choice.

7.4.5 Further comments

During the discussions that took place during the stakeholder events with the healthcare professionals and the physician it was noted that the results from the three studies and the 'future scenario' had some practical implications for their practice.

> *"This has given us a better understanding of the impact of the device [we provide] and we will definitely keep it in mind when talking to patients . . . we should look for opportunities to ask more questions regarding the impact on patients' lives and check their understanding of what they have been told".*

The physician (who was associated with the home intravenous antibiotic service) extended an invitation to present the results of the studies to other members of the service:

"You should present these findings to the nurses in the clinic. If we can think of ways to mitigate these issues it may improve adherence to the therapy and treatment success".

Interestingly the physician repeatedly mentioned the link between the findings of this thesis and adherence. This suggests that in order to encourage some healthcare services to change their practice there may need to be some discernible or quantifiable health benefit.

7.5 Summary

This chapter has described the results of four events in which the findings of the previous three studies were presented to a variety of stakeholders of home medical devices. A 'utopian future scenario' based on those studies, was also presented.

The feedback from healthcare professionals on the findings of study one recognised that there were issues associated with the use of medical devices in the home. This study went on to highlight the issues surrounding the impact medical devices had on the aspects of the home environment that they had not previously considered or been aware of.

The conclusions of the second study, whereby the device characteristics can be thought of as being either practical in nature (that can enable or enhance use) or related to satisfaction were also supported by stakeholders.

The feedback received from all three studies highlighted a propensity for the adoption of a more paternalistic, bio-medical approach to the provision of home medical device.

The results provided the stakeholders who worked in healthcare with new knowledge regarding the impact that medical devices can have on users, their partners and the home in which they live. The use of a future scenario provided a focus for discussion about how these findings fitted in to the day to day running

of services that they had experience of. It also allowed stakeholders to identify and discuss opportunities and barriers to the suggestions that emerged from the results of the three previous studies.

The stakeholder events in this chapter proved to be a particularly useful method to disseminate the findings of the research and demonstrate the general acceptance of the research findings, identified areas that resonated with stakeholders and indicated that the healthcare professionals were learning things that they did not know about how the devices were used and understood by users and their partners.

Chapter 8: Reflections and learning points from interviewing participants in their own homes

8.1 Introduction

This chapter describes the challenges associated with interviewing participants in their home encountered during this research. It provides suggestions and ideas for other researchers on how they may navigate similar research areas, including:

- Issues around recruitment of patients for healthcare technology studies.
- Specific issues and opportunities that arise from conducting research in the home environment.
- Dealing with emotions when conducting studies directly with patients.

8.2 Recruitment: negotiation and networks

Recruitment of participants for any study can be challenging and gaining access to potentially vulnerable groups (for example, older people, persons suffering illness or children) can be particularly difficult (Sutton et al, 2003).

It is important to consider different recruitment strategies when planning a study and applying for ethical approval. I initially started recruitment for my first study by advertising the study with posters placed in the university and in targeted locations where I considered it likely that they would be seen by my target participant group (which was people 65 years old or over that used medical devices in the home), such as Post Offices, shops, and churches. I also placed an advertisement in the local press. While these approaches did produce some interest the number of participants recruited was disappointing.

I then tried a different approach, which involved approaching patient and older people's groups. These groups often place advertisements in local newspapers about events or to recruit new members. This recruitment strategy required a

great deal of negotiation with gatekeepers to access these groups, a topic which has already been discussed in chapter four. I found that it was difficult to build a rapport and gain the trust of these gatekeepers via email or telephone and in hindsight face to face meetings with local organisers may have been more productive.

On reflection, the reluctance of gatekeepers to get involved may in part be because they could be seen to be endorsing the study. They may then feel responsible for participant's wellbeing as a result of taking part in the research. In the same way the national charity groups that were approached to promote the research required the study proposal to be reviewed by their senior management, meetings with local gatekeepers could have been organised with an emphasis on how the ethical approval process had been satisfied. Furthermore participant information sheets could be designed that state clearly that the gatekeeper does not endorse or is not responsible for any aspects of the study.

The lack of positive responses led to me becoming frustrated with the recruitment process. I could not understand people's reluctance to get involved (either by promoting the study or becoming a participant) given the relatively uncomplicated nature of taking part and that we were offering a reasonable "inconvenience allowance" of £10 shopping vouchers. Gaining access to older people can be difficult at the best of times but I believe that it was more difficult because I was interested in health-related issues. Whether this is because older people with health issues feel increasingly vulnerable and wary is not clear but it certainly added a layer of complexity as I had to liaise with people whose role was to protect this particular group of individuals. I then began to wonder if there was anything I could do to make myself more acceptable to potential participants? In the UK, working with vulnerable people in an official position requires a Disclosure and Barring Service (DBS) check (previously called Criminal Records Bureau (CRB)) in a bid to prevent unsuitable people from working with vulnerable groups. In a bid to ease any concerns the individuals or groups may have had, I applied for a CRB check through the university. While I was never

asked to produce my CRB documentation, I did mention my CRB clearance whenever possible as I felt I needed to do as much as I could to alleviate people's concerns and increase my own credibility with people involved with older people.

The recruitment method that proved the most successful for my research was snowball sampling (getting participants to recommend/introduce other participants), which is an often used "tactic" to reach "hidden" or marginalised populations (Noy, 2008). The wife of one participant in study one (chapter four) was an active member of the community and other people participated in the study as a result of her recommendation. It is this kind of opportunity that highlights the importance of networking and making a good impression on people to help with the challenges recruitment brings.

Recruiting participants to interview in their own homes for the longitudinal study described in chapter six also presented problems. The clinic I chose to recruit from was a community hospital that ran oxygen clinics twice a week. My original inclusion criteria of identifying participants prior to being provided with an oxygen concentrator proved to be particularly restrictive and I often spent days in the nurses' office with no patients meeting my particular requirements. Establishing and maintaining a good relationship with the staff was very important and ways of facilitating these types of relationships have been described by Taneva et al. (2015). So instead of me travelling to the clinic and sitting in the office all day the staff suggested that they email me the day before the clinics to let me know if there were any potential patients being assessed that day, in order to reduce my non-productive time spent on site.

I also took the decision to widen my inclusion criteria to include participants who had received the oxygen concentrator within the previous eight weeks as recruitment was proving to be particularly difficult. This was a hard decision to make but without this change it would have been unlikely that the work would have been completed within the time frame of needed to complete a PhD.

What I really learned from this experience is to persevere. It is important to work hard at establishing and maintaining relationships with gatekeepers and healthcare staff as this can be pivotal in reaching potential participants. You also need to be flexible and adapt to the challenging situations that can occur during the recruitment process, for example using different types of sampling methods to reach potential participants and being prepared to make changes to inclusion/exclusion criteria.

8.3 Participant and interviewer safety

A different kind of risk assessment is required with fieldwork conducted in the home as opposed to those that take place in a more traditional healthcare environment. Not only do participants need to feel safe but the safety of the interviewer also needs to be taken into consideration.

For vulnerable people, inviting strangers into your home can be a source of anxiety, especially if you live on your own. In order for the participants to feel safe in this situation, all were offered the option of having a chaperone present during the interview. However, none felt they needed this provision. Most of the participants in my research lived with a partner or spouse who was present at the time, which itself gave rise to issues which will be discussed below.

With regards to the safety of participants, I was very aware that older people, and particularly people with certain illnesses, are less capable of fighting infections. With this in mind I carried some alcohol gel hand wash which I used before and after visiting people's homes to avoid inadvertently passing on or receiving potential infections. I was also aware that I may have to cancel meetings with participants if I felt the least bit unwell. From my previous experience in healthcare I know that people with Chronic Obstructive Pulmonary Disease would not be keen on interacting with someone who may have a slight cough or cold.

Having previously worked in a community healthcare role, I was particularly aware of how important it was to consider the safety of the interviewer when

visiting people in their own homes. These considerations should include the travel to and from the interview as well as entering an unfamiliar environment.

I mainly used public transport so all trips were planned well in advance and I carried timetables and maps with me. In order to avoid becoming a target for theft while travelling, objects such as laptops and mobile phones were kept out of sight and a lone working procedure was adopted where someone would know where I was going and would receive a phone call after the interview to confirm that all was well.

The safety of the interviewer within the participant's home also requires consideration. For example, one participant in our study owned a large dog. I have to admit that I do get nervous around dogs that I do not know. I had a bad experience in my previous job where I was growled at for an hour while I was trying to help its owner which has done little to help my confidence. Seeing the participant's dog made me very nervous and I just wanted to leave. Knowing I would be unable to concentrate and give the interview my full attention, I asked if the dog could be kept in another room while the interview took place. This had to be negotiated with sensitivity, as the dog was a treasured member of the household.

I learned that when conducting research in the home environment you are very much responsible for both the participants' and your own safety and that this entails the need to continually risk assess.

8.4 Healthcare interviewing

The research interview has been defined as a "professional conversation" in that it is not a "conversation between equal partners" as the aim is to elicit information from the participant (Kvale, 1996).

However, it has been suggested that this method of interviewing perpetuates the disempowerment of vulnerable groups and that an equal or dialogical approach should be taken (Russell, 1999), which is what I did my best to achieve.

The interviews in my studies certainly benefited from this second approach in terms of rapport building and breaking down barriers between interviewer and interviewee in an attempt to get participants to speak openly. I found it is better to approach the interview as more of a social encounter. While a brief telephone call or email may have confirmed that the participant met the inclusion criteria for the study, it is only after knocking on the door and being invited in that you meet each other for the first time and it is this period that will set the tone of the interview.

After usually being offered a drink, I would engage in some small talk ("looks like it's going to rain again!" or "is that a picture of your grandchildren?") to put the participant and myself at ease before going through paperwork, gaining consent, and starting the interview proper.

After the interview had ended, I continued with the small talk while packing away equipment and sorting out paperwork. This seemed a more natural way to finish the visit, rather than briskly gathering things together and rushing off, which could leave the participant feeling unhappy or disappointed with the whole encounter.

The nature of questioning in the main part of the interview was to allow the participants to tell their own story. In quantitative research participants tend to be given questions that are closed i.e. the answer choices are either given to the respondent or understood by the respondent. In qualitative research open questions are used that allow the respondent to answer without presented or implied choices. It was important during the interviews I conducted to try and keeps the conversation focused on the topic in hand while giving the participants room to define the content of the discussion. This allowed them to provide information that was important to them without imposing myself into the interaction so much that the data was more a reflection of my own preconception.

The use of diaries in the study described in chapter six proved to be problematic. While this could have been a useful way to collect participants' experiences only

one participant used this tool. I felt that pushing or insisting in the use of the diaries would have preserved a sense of researcher as expert and undermined all my attempts to empower participants and promote a feeling of equality.

8.5 Considerations in using the home environment

In direct contrast to the controlled environments of laboratories, being invited into another person's personal and private space relinquishes much of that control to the participant and the influences of outside sources. In my studies, all but two interviews were carried out in participant homes.

As mentioned previously, having the partner/spouse present in the room during the interview presented its own challenges. The partners encountered in the first study showed more than a passing interest in the research and were keen to listen in on the interview. It would have been awkward to have to exclude a person from a room in their own house and, if the participant agreed, then the partner stayed in the room while the interview took place. These partners, however, were not silent observers and in fact contributed what turned out to be rich data to the study. It was clear that it was not just the patients (as users of medical technology in the home) that were interacting with these devices but the partners were also affected. It quickly became apparent that we needed to also gain consent from the partners in order to use the data. It was acknowledged, however, that interviewing the user and partner together might have resulted in a less open and frank discussion.

Interviewing couples was quite challenging. In adopting a relaxed conversational approach to the interview it was difficult to maintain a balance between giving participants the space to explore and discuss their feelings and experiences and not allowing the conversation to veer too far off topic for long periods of time. I was, however, put in some quite awkward situations when couples started to argue with each other in front of me. While this felt uncomfortable it did provide data that contributed to the research findings and so I learned that rather than diffuse the situation at the earliest opportunity (which could also be construed as

imposing my authority which I was trying not to do), it was better to give people the space to be who they were and the freedom to express themselves.

Carrying out research in the home did have advantages, however. The participants in this study were very keen to show me their medical devices, where they were kept, and how they were used. As I was interested in the integration of these devices into the lives of participants, these "in the field" revelations were instrumental in stimulating further questions and prompts to the semi-structured interviews.

An important thing I learned conducting research in the home environment is the need for adaptability. While fieldwork in participants' homes is unpredictable and a lot of the time you will be led by the situation, it may also present opportunities not found in other environments that may be of benefit to the study.

8.6 Emotional challenges

Talking about medical related topics and interviewing participants with medical conditions can invariably stir emotions in both the participant and the interviewer that may affect the interview.

I found that I needed to be sensitive to the participants' emotional state and on occasion had to modify the order in which questions were asked. For example, one gentleman with a respiratory condition became tearful when explaining how his health was responsible for the loss of long-held friendships and the reason he was unable to keep his pets. As a result, I shifted the focus of the questions from negative to more positive aspects of what the medical device had enabled him to do. The negative aspects were revisited later in the interview and framed in different ways. While it would be unethical to offer advice to participants who were upset, I felt it was appropriate to provide all participants with the contact details of support organisations.

It can be difficult to be invited into people's lives and homes and not become emotionally attached to your participants. The nature of the interviewing technique used in my research encouraged entering into the participant's 'lifeworld' (Smith et al., 2009), developing empathy, trust and rapport. This was particularly noticeable during the interviews with participants in the longitudinal study. Conducting research when people are at potentially their most vulnerable can mirror that of counselling or psychotherapeutic relationships. All the interviewees talked about loss, and death was a frequent topic raised by participants. Having participants express some quite personal feelings can be emotionally demanding. I had previously worked with older people in the healthcare setting and I felt this experience was extremely valuable in engaging with these emotions. I also allowed myself time to reflect on the emotional issues that arose in each interview and I had the opportunity to regularly debrief matters with a supervisor. I was also aware that the university provides counseling services for students.

The process of ending the participant/researcher relationship after the study can also be an emotional time that is worth considering. Having spent time working at and developing a relationship conducive to open and frank discussions with both the single and longitudinal interview participants, I did not want participants to feel that they had experienced a "hit-and-run" interview. At the same time I did not feel it was appropriate to impose myself upon people any more than they felt comfortable with. This issue has been discussed by other researchers, for example Cutcliffe and Ramcharan (2002) offered participants the opportunity to attend seminars intended to disseminate results and Booth (1998) describes how she believes that conducting participatory research with people with learning difficulties is not only about inclusion but also about a longer-term commitment and has been in contact with some of the individuals 11 years after the study. My very modest strategy involved sending a thank you card a couple of weeks after the final interview. In the card I once again gave my thanks for taking part in the study and reiterated that they should feel free to contact me if they wanted to discuss any issues regarding the research or the

things we spoke about. I hoped that this would allow them to choose the ending of participation.

Healthcare as an emotive subject is one that can affect both the participant and the interviewer. I found that spending a little time thinking and preparing for these issues helped make a potentially difficult or painful encounter more comfortable for both myself and the participants.

8.7 Conclusion

Fieldwork, especially when carried out in people's homes, presents many challenges not normally encountered with lab-based studies. Recruitment of potentially vulnerable groups and being invited into participants' lives as part of the research involves the transfer of control to a large extent to other people.

While meticulous planning is required for any type of study, I found that being flexible enough to react to changing circumstances, as and when they occurred, was the key to the successful completion of this type of research. I hope that my reflections and the learning points covered here will help other researchers to deal with some of the difficulties that can be encountered when conducting research in the home environment.

Chapter 9: Conclusion

9.1 Introduction

This final chapter will summarise the research presented in this thesis, set out the contributions to knowledge, provide a discussion of the limitations of this research, and close with potential avenues of research that may build upon this work.

9.2 Summary of the research

At the start of this investigation little was known as to the impact medical devices had upon the home environment, users and their partners. This final chapter discusses the academic contribution of this research and how the gaps in knowledge have been addressed. In chapter two the following research questions were posed as a result of the literature review:

- How are medical devices integrated into the homes of users?
- What do different groups of healthcare professions consider important in relation to home medical devices?
- What is the lived experience of couples who are given a medical device to use at home and how does this change over time?

The outcomes of the research are presented in five chapters: Chapter four, Chapter five, Chapter six, Chapter seven and Chapter eight.

Chapter four described the results of an exploratory, qualitative interview study looking at the integration of medical devices into the home environment. This study identified and described some of the challenges faced by users and their partners in relation to medical device use in the home. In particular, it considered the impact of medical devices on the physical, personal and social experience of home.

Chapter 5 described the results of an online questionnaire that was given to different groups of healthcare practitioners and device users/non-users in order

to rank nine factors or characteristics associated with home use medical devices in order of importance. Open questions were also use to help clarify the quantitative findings.

Chapter 6 presented the results of a longitudinal, qualitative interview study with couples where one person had been diagnosed with chronic obstructive pulmonary disease and had been given an oxygen concentrator to use in the home as part of their treatment. It found that there is a process to go through with regards to adjusting to having an oxygen concentrator in the home and that different issues had to be negotiated as the couples adjusted to their changing lives.

Chapter seven described four stakeholder feedback events that were arranged in order to disseminate the findings of the studies, validate and obtain feedback on those findings and then use the feedback to help contextualise these findings in relation to current healthcare practice.

Chapter eight contains a personal reflection on some of the challenges encountered during interview-based studies conducted in this research. It provided suggestions and ideas for other researchers on how they may navigate similar research areas.

9.3 Reflections on research questions and contributions to knowledge

In addition to answering the research questions posed at the outset of this thesis, this research has made significant contributions to the field of home use medical devices.

9.3.1 The first research question: How are medical devices integrated into the homes of users?

While there is little support for a rigid definition of 'home' the literature review identified that home is more than a mere physical space or object but can be

regarded as a special place that is imbued with emotion and personal meaning. Authors have proposed different physical, personal and social aspects or qualities that homes may possess that may influence people's experience of home. A working model was proposed based on a synthesis of the different aspects or concepts of home identified in the literature review (Chapter two).

The previous literature that has considered the use of medical devices in the home identified that there is a sense that medical devices intrude into the home environment and do not fit in. The impact on the home has mainly been discussed in relation to the physical characteristics of the environment. Through addressing the first research question, this research has contributed to knowledge by identifying and describing the impact of medical devices in relation to different aspects of the home environment that have not previously been considered. The studies described in chapters four and six have identified the ways that medical devices can influence the physical, personal and social aspects of the home environment as described in the working model of aspects of home set out in literature review (chapter 2). For example the themes *the accommodating home* (chapter 4) and *making space in their lives* (chapter 6) illustrates the influence medical devices have on the experience of the physical aspects of home. The themes *striving to maintain control* and *evoking different emotions* (chapter 4) and *negotiating new freedoms and restrictions* (chapter 6) describe how medical devices can both foster and threaten peoples personal experience of home in terms of emotion and feelings of control. These relate to the aspects of home concerned with 'offering security and safety' and 'promoting a sense of control' proposed by the working model. Furthermore, the themes *the social device* (chapter 4) and *negotiating changing relationships* (chapter 6) describe the different ways in which the device impacted on the aspect of home as a 'place to foster relationships' and relates to the social experience of home.

These results illustrate that there are similarities between the effect medical devices have on the home environment and the effect of home modifications undertaken to encourage independence and make activities of daily living easier

for those physically impaired by accident or illness. In doing so, this work has built on the work of Heywood (2005); Tanner et al. (2008) and Aplin (2013) in terms of the transformative effect adaptive equipment and modifications have on the home environment and demonstrated that their conclusions can be extended to medical devices.

This research also extends the work of Ingadottir and Jonsdottir (2006); Lehoux (2004); Fex et al. (2009) by highlighting the psychosocial impact of medical devices, rather than concentrating solely on issues relating to safety or function. This work builds on their recommendation that, as home care involves more than simply transferring a particular technology from the hospital to the home, it requires education and support of patients to enable them to lead a healthy and personally satisfying life.

Avril-Sephula et al. (2014) highlighted the emotional challenges of living with a partner on haemodialysis. This research has extended this work by looking at the emotional effects of home medical device use over time and has investigated how couples cope with this significant change in circumstance.

The results from the stakeholder events demonstrate that answering this research question generated knowledge of which this particular group of medical device providers were unaware. In particular, that bringing a medical device into the home environment raised particular concerns for partners of the device users.

This research has shown that the home use medical devices can profoundly affect people's experience of home. It has also suggested that a more holistic approach to home medical device provision could be achieved by understanding and valuing the fact that patients and their partners experience home as a place which incorporates physical, social and personal dimensions, not just as a space. This thesis has also made practical suggestions about how this can be achieved, for example, by incorporating an 'aspects of home' checklist, similar to the working model proposed in chapter two, which could be used by medical device

providers as a basis to ascertain the suitability of a particular medical device being considered for a particular household.

9.3.2 The second research question: What do different groups of healthcare professions consider important in relation to home medical devices?

The most usual way for people with chronic conditions to acquire a medical device is via a healthcare professional. The literature acknowledges that healthcare is a complex system that comprises different groups of professionals working in different parts of the healthcare system (for example primary and secondary care). It is not clear from the literature, however, what the priorities of these groups are when providing a medical device to use at home and whether they differed between different groups. For example to what extent, if at all, is the home environment considered when prescribing medical devices?

While the results of this study did not support the hypothesis that there would be a difference between the hospital-based and primary care practitioners in terms of the relative importance of factors related to home medical devices, it does contribute to the understanding of aspects of home medical device provision.

The first finding of this study was that the factors which professional groups generally agree are most important are not the same as factors that have been identified in the literature or that were identified by the qualitative studies presented in chapters four and six. The importance of practical factors (user testing, clarity of instructions, undergoing clinical trials, reducing clinic/GP appointments, user training and cost effectiveness), compared to the lack of consideration of factors concerning the home environment, choice and appearance by the different professional groups indicates a lack of a whole person approach to patient care and a more paternalistic approach to selecting medical devices to be used in the home.

The second finding of this study was that, in general, the characteristics toward the top of the rankings seem to be related to the practicalities of device use and the characteristics positioned in the lower part of the table seem to be more related to user satisfaction. While the 'satisfaction' factors concerning choice, appearance and the impact on the home environment were consistently ranked low by all participant groups in the forced choice section of the questionnaire, the answers to the open questions indicated that they were not without some value to participants or had some effect on behaviour.

This study has highlighted that patient choice and empowerment is lacking during the provision of home use medical devices and that factors that may facilitate satisfaction with devices (e.g. home environment and lifestyle factors) are not given significant consideration by healthcare professionals. The characteristics ranked highly by participants seem to be related to the practicalities of medical device use which is more in keeping with a traditional approach towards promoting compliance with treatments to improve clinical outcomes. While much has been written around models of care and government policy with regards to a more multi-disciplinary, person centred delivery of care for people with chronic diseases (e.g. Wagner et al., 2001; DoH, 2005; Novak, 2013), this study has suggested that at least as far as medical devices are concerned, a more paternalistic approach as to what is important in selecting a device has been adopted. However, the findings of Coulter and Ellins (2006); Stiggelbout (2015) and Vermeire et al. (2001) have highlighted the importance of patient-focused interventions in terms of long term better treatment adherence and outcomes. This was supported by the feedback from the stakeholder events, which illustrated that medical professionals could see the benefit of acknowledging patient's environments and life-style with regards to the provision of medical devices if there was a tangible benefit with regards to treatment adherence.

9.2.3 The third research question: What is the lived experience of couples who are given a medical device to use at home and how does this change over time?

This research question was addressed by extending the work undertaken in chapter four and investigating how medical devices are integrated into the homes of users and the impact on different aspects of home. This study, described in chapter 6, adopted an in-depth, longitudinal approach that focused on one particular home use medical device - an oxygen concentrator - and how couples experienced having the device enter their lives and homes.

By addressing this question this research makes a contribution to knowledge by investigating an area that had not been previously studied, namely, whether the issues associated with home medical device use raised in the literature were stable or were likely to change over time. This study has found that there is a process to go through with regards to adjusting to having an oxygen concentrator in the home and has identified the different issues that have to be negotiated as couples adjust to their changing lives over time. This supports and builds on the findings of Berg and Upchurch (2007) that couples coping with chronic illness may together appraise and cope with illness in the long-term but also in terms of the day to day aspects of illness management.

This research supports the work of Mishel (1997) and Neville (2003) on the role of uncertainty and coping. It has demonstrated that, in contrast to the relatively predictable and chronic nature of COPD, being given an oxygen concentrator represents an acute episode resulting in uncertainty for couples that requires the adoption of different coping strategies in order to adjust to this new situation. The ease with which these couples adjusted to life with the oxygen concentrator appeared to be mediated by the expectations that they had about the device. These findings led to the conclusion that the education that patients receive should not only concern the practicalities associated with a device but also cover the psychological and social impact, in order to guide patient expectations. This

builds on the recommendations of Croxton and Bailey (2006) and Doherty and Petty (2006) in terms of improved delivery of long term oxygen services.

The stakeholder events found that these findings resonated with healthcare practitioners. This led to recommendations being made for how these findings could be used to improve practice, specifically with regards to the information given to patients; specifically that information needs to be tailored to include content that addresses the needs and expectations of patients and their partners.

9.2.4 Learning points from interviewing participants in their own homes

Conducting research in healthcare is a challenging undertaking and recruiting and involving potentially vulnerable groups outside of a traditional healthcare environment (e.g. hospital or clinic) brings with it a unique set obstacles. Most academic research papers include a methods section which describes what was done to answer the research question and how the results were analysed, however, there is not the space within research articles to consider or describe methodological challenges or advice and guidance in finding solutions to problems that may be encountered (Kallet, 2004).

In Chapter 8 this thesis has set out some of the challenges encountered while conducting this research that are not normally covered in traditional journal papers and described how they were overcome and how they affected the design of the research. These challenges included issues around participant recruitment and how safety of both the researcher and participant needs to be considered during research in the field. It also considered the emotional wellbeing of both parties when conducting healthcare research. The purpose of including these reflections and learning points was to provide suggestions and ideas that other researchers conducting similar research may learn from.

9.3 Reflection on findings and future work

In answering the research questions posed at the outset of this thesis, this research has identified and described a number of ways in which medical devices can affect the experience of different aspects of home. It has shown that these factors can influence how satisfied patients and their partners are with devices. It has also shown that these factors are considered by all groups to be important, although they are not considered as important as factors such as effectiveness, cost and training and so are currently unlikely to be addressed when medical devices are being considered for use in the home.

This research has shown that being given a medical device to use in the home can represent a sudden episode of uncertainty or anxiety for couples that can result in the adoption of maladaptive coping strategies in order to adjust to this new situation. These issues have implications for the medical management of chronic conditions in terms of improving the health and quality of life of people with long-term conditions. The question of how and why they can be addressed should be the focus of future research.

One way in which patient and partner uncertainty and anxiety could be lessened is through the use of patient stories. This thesis has identified the important role the right type of patient education has in managing expectations and adjusting to life with a medical device and that learning from peers can be particularly useful. Providing potential and new device users with the experiences and stories from patients and partners who have gone through a similar process should form part of a multifaceted education package aimed at facilitating the transition to living with a medical device in the home.

Future work could use the findings from this thesis to inform the development of an assessment tool or checklist for home medical devices (based on the aspects of home working model described in the literature review) that could be used, in collaboration with the household concerned, to judge the suitability of a medical device. Such a process could inform the selection of a more suitable device or

alternatively (as the findings from the questionnaire suggest that cost and availability are often deciding factors in selecting a suitable device) be used to tailor an education package to manage the expectations of patients and partners about the device in order to ease the transition as they adjust to their changing lives.

This research has found that the 'satisfying' factors associated with the home environment are not considered by healthcare professionals to be as important as effectiveness, cost and training and this may be due in part to the fact that these aspects – and their effects – are difficult to quantify. However, the healthcare practitioners who participated in the stakeholder events frequently mentioned that these factors are likely to have an effect on treatment adherence. Future work, therefore, could focus on the potential clinical consequences (improved health outcomes through improved adherence) and cost consequences (fewer wasted resources due to device abandonment) of an improved consideration of these satisfying factors.

The implications of the research reported in the thesis in terms of capturing the experiences of medical device users and the feedback received from the healthcare professionals in the stakeholder events points to possible use of experience-based co-design to rethinking care delivery in terms of the use of home medical devices. Experience-based co-design (EBCD) is an approach that involves gathering experiences from healthcare staff and patients (carers or loved ones) to co-design services and care pathways together (The Kings Fund, 2013). The findings reported in this thesis suggest there are areas where there is a disconnect between what couples want or need and the service currently provided (in terms of consideration of the home environment or the content of education) which through experience-based co-design could be overcome.

9.4 Limitations of the thesis

There are some points to consider in relation to the limitations of the studies presented in this thesis.

First, due to the difficulties encountered in recruiting participants for the qualitative interviews a relatively small number of participants were included in these studies. This did allow the detailed examination of each participant's particular case which enabled a rich, nuanced and comprehensive analysis of the data which conveys a sense of quality and texture (Smith et al., 2009).

In relation to the transferability of findings in qualitative research, Willig (2008) has argued that small sample sizes often mean that the research findings cannot be widely generalised, meaning that immediate claims made are bounded by the group that has been studied. Therefore, although the findings of the qualitative studies say something about the experiences of couples aged 65 years and over using a medical device in the home, they cannot be easily generalised to the wider population of, for example, singles aged 65 years living in a nursing home or adolescents living at home with parents. However, Willig (2008) also notes that while it is unclear who or how many other individuals share a particular experience that is described in qualitative studies with small sample sizes, those studies do demonstrate that the experience is nevertheless available within a particular culture and society.

In a similar way, the types of medical devices used by the participants in these studies may also limit the generalisability of the findings. Medical devices can be grouped in different ways, for example, according to size, purpose (monitoring or treatment delivery), acquisition (NHS or self-sourced) or duration of use (weeks, months, years). It is likely that different types of devices exert different influences on users' experience of home and so care should be taken when attempting to generalise the finding s of this research to other devices. Whilst the findings from the longitudinal study may be comparable in some ways to other large and intrusive devices, for example, home dialysis or mechanical

ventilators, they may be less similar to the influence exerted by smaller devices such as blood pressure monitors. Both of these limitations indicate the need for further research.

9.5 Concluding statements

The aim of this thesis was to investigate the transformative effect medical devices have on the home environment, how users cope with being given a medical device and the importance given to different aspects of medical devices used in the home. To achieve this, this research has engaged with the perspectives of patients, their partners and healthcare professionals in three separate studies of home use medical devices. Firstly, it provides an account of the impact medical devices have in relation to the physical, personal and social experience couples had of the home environment. Secondly, it demonstrates that couples adopt different coping strategies as they adjust to being given a medical device and that the adjustment process appears to be mediated by the expectations that they had about the device. Finally, this thesis has set out learning points, advice and guidance related to conducting healthcare research in people's homes based on the experience accrued through this entire research project.

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Appendices

Appendix 1 Study 1 interview schedule

Study 1. Interview Schedule.

Questions

1. Tell me about your device/devices

- When and how often do you use it? Is this as recommended?
- Where do you use it?
- Where is it kept when not in use?
- Did you decide which device? if so what were the deciding factors?
- What do you consider to be important factors in choosing a medical device?

2. Tell me about your home

- How long have you lived here?
- Do you have many visitors/family that visit?
- What does 'home' mean to you?

3. Think back to when you first got your device, how did it feel when you got it home?

4. How has this medical device fitted in to your life and those you live with? Has anything changed?

- Do you go out/stay in more?
- Has the way or how often you use rooms in your house changed?
- Have your routines altered?

5. How does using the device make you feel?

6. How, if at all, do you think *you* have changed since you received the medical device?

7. How do you think other people view your device?

8. Describe some of the positive feelings associated with the medical device

9. Describe some of the negative feelings associated with the device

10. What if anything would you change about the device and why?

11. What advice would you give to a friend or family member who needed a similar device?

Appendix 2 Example of questionnaire

Over 65's

Introduction

This study is being conducted by The University of Nottingham as part of a PhD project investigating the impact of home use medical devices on the lives of older people.

Taking part in this study will involve completing a questionnaire that asks about your attitudes and experiences involving medical devices. Most of the questions will involve making a choice from a set of options, while three questions require you to write a short answer. The questionnaire should take about 10 minutes to complete.

For every questionnaire completed £1.00 will be donated to The British Lung Foundation up to a maximum of £200.

The purpose of this questionnaire is to elicit the views of different people involved in the medical device 'lifespan' (that is the different stages medical devices go through from design and manufacture until they are finally disposed of at the end of their usefulness).

Participation in the study is entirely voluntary. You can withdraw from the study at any time without having to provide a reason. If you do withdraw, any answers you have given will be destroyed and the information will not be used in our analysis.

All information which is collected about you during the course of the research will be kept strictly confidential and our procedures for handling, processing, storage and destruction of your data are compliant with the Data Protection Act 1998 and Safe Harbor guidelines. This research is being organised by The University of Nottingham.

The study is funded by the UK Engineering and Physical Sciences Research Council.
The study has been given approval by The University of Nottingham, Faculty of Engineering Ethical Review Committee.

Page exit logic: disqualify
IF: Question "Which of the following best describes your current situation?" #2 contains any ("None of the above") **THEN:** Disqualify and display:
Sorry, you do not qualify to take this survey. For further information on The Multidisciplinary Assessment of Technology Centre for Healthcare (MATCH) at The University of Nottingham please visit http://www.nottingham.ac.uk/match/

1. Should you wish to withdraw from the study we need to identify your replies so that we may remove and delete your data. In order for us to do so you need to generate a unique code consisting of the last two letters of your family name and last two digits of your phone number:

eg Smith 1234 would be th34 *

2. Which of the following best describes your current situation? *

- I am over 65 and do not currently use a medical device
- I am over 65 and currently use a medical device (hand-held inhalers are not considered a medical device)
- None of the above

3. What age are you? *

4. Are you... *

- Male
- Female
- I prefer not to answer

5. If you use a medical device at home which medical devices do you currently use?

Instructions

We would like to get your opinion on different aspects of medical devices that are used in the home. In particular we are interested in devices that are likely to be given to people by doctors/nurses/pharmacists. This wide range of devices may include such things as blood pressure monitors, nebulizers, infusion pumps, oxygen concentrators and dialysis equipment.

Please think of one particular type of medical device that may be used in the home by patients or their carers.

6. Which device do you have in mind? *

7. What experience or knowledge do you have of this device? *

You are going to be asked to select the more important medical device characteristics from pairs of choices.
For example if you think a) "*That the device has been tested by relevant users*" **is more important than** b) "*the device is cost effective*" **then you should select** 'a)'.

Please answer these questions in relation to the medical device you identified on the previous page and select the answer that you feel is more important to you personally.

We recognise that there are a lot of comparisons to make but please answer the questions as best you can. The answers you give are very important.

*You are required to answer all the questions- if a question is missed, when you click the 'next' button, you will be returned to the question page and the missed question will be highlighted.

8. Please select the most important *

- ○ The instructions are sufficient to enable correct use
- ○ The device has been tested by real users

9. Please select the most important *

- ○ Users receive training prior to use
- ○ The device has been tested by real users

10. Please select the most important *

- ○ The device is cost effective
- ○ The device has been tested by real users

11. Please select the most important *

- The device has undergone clinical trials
- The device has been tested by real users

12. Please select the most important *

- The device has been tested by real users
- The device reduces clinic/GP appointments

13. Please select the most important *

- The device has little impact on the home environment
- The device has been tested by real users

14. Please select the most important *

- The outward appearance of the device
- The device has been tested by real users

15. Please select the most important *

- The device has been tested by real users
- The patient is offered a choice between different models of the same type of device

16. Please select the most important *

- The instructions are sufficient to enable correct use
- Users receive training prior to use

17. Please select the most important *

- The device is cost effective
- The instructions are sufficient to enable correct use

18. Please select the most important *

- The device has undergone clinical trials
- The instructions are sufficient to enable correct use

19. Please select the most important *

- The device reduces clinic/GP appointments
- The instructions are sufficient to enable correct use

20. Please select the most important *

- The device has little impact on the home environment
- The instructions are sufficient to enable correct use

21. Please select the most important *

- The instructions are sufficient to enable correct use
- The outward appearance of the device

22. Please select the most important *

- The instructions are sufficient to enable correct use
- The patient is offered a choice between different models of the same type of device

23. Please select the most important *

- The device is cost effective
- Users receive training prior to use

24. Please select the most important *

- Users receive training prior to use
- The device has undergone clinical trials

25. Please select the most important *

- The device reduces clinic/GP appointments
- Users receive training prior to use

26. Please select the most important *

- Users receive training prior to use
- The device has little impact on the home environment

27. Please select the most important *

- Users receive training prior to use
- The outward appearance of the device

28. Please select the most important *

- The patient is offered a choice between different models of the same type of device
- Users receive training prior to use

29. Please select the most important *

- The device has undergone clinical trials
- The device is cost effective

30. Please select the most important *

- The device reduces clinic/GP appointments
- The device is cost effective

31. Please select the most important *

- The device has little impact on the home environment
- The device is cost effective

32. Please select the most important *

- The outward appearance of the device
- The device is cost effective

33. Please select the most important *

- The device is cost effective
- The patient is offered a choice between different models of the same type of device

34. Please select the most important *

- The device has undergone clinical trials
- The device reduces clinic/GP appointments

35. Please select the most important *

- The device has undergone clinical trials
- The device has little impact on the home environment

36. Please select the most important *

- The outward appearance of the device
- The device has undergone clinical trials

37. Please select the most important *

- The patient is offered a choice between different models of the same type of device
- The device has undergone clinical trials

38. Please select the most important *

- The device reduces clinic/GP appointments
- The device has little impact on the home enviroment

39. Please select the most important *

- The outward appearance of the device
- The device reduces clinic/GP appointments

40. Please select the most important *

- The patient is offered a choice between different models of the same type of device
- The device reduces clinic/GP appointments

41. Please select the most important *

- The device has little impact on the home environment
- The outward appearance of the device

42. Please select the most important *

- The device has little impact on the home environment
- The patient is offered a choice between different models of the same type of device

43. Please select the most important *

- The outward appearance of the device
- The patient is offered a choice between different models of the same type of device

Open questions

Please answer the following questions in more general terms and not purely in reference to the device you thought about in the previous section

LOGIC Hidden unless: Question "Which of the following best describes your current situation?" #2 contains any ("I am over 65 and currently use a medical device (hand-held inhalers are not considered a medical device)")

44. Were you offered a choice between different types of the medical device/s you currently use? If so, what did you consider when making that choice? *

LOGIC Hidden unless: Question "Which of the following best describes your current situation?" #2 contains any ("I am over 65 and currently use a medical device (hand-held inhalers are not considered a medical device)")

45. What effects, positive or negative, has the device had on your life? *

LOGIC Hidden unless: Question "Which of the following best describes your current situation?" #2 contains any ("I am over 65 and currently use a medical device (hand-held inhalers are not considered a medical device)")

46. If you could change anything about your device/s what would that be? *

LOGIC Hidden unless: Question "Which of the following best describes your current situation?" #2 contains any ("I am over 65 and do not currently use a medical device")

47. If you had to use a medical device at home (for example a nebuliser to help you breath medication in to your lungs or an infusion pump to administer drugs in to your circulatory system) would you like to be given a choice between different models of the same type of medical device you had to use? If so what sort of things would you take into consideration when making that choice? *

LOGIC Hidden unless: Question "Which of the following best describes your current situation?" #2 contains any ("I am over 65 and do not currently use a medical device")

48. If you had to use a home use medical device, would you look into the different types that are available? If so how would you do so? *

Logic Hidden unless: Question "Which of the following best describes your current situation?" #2 contains any ("I am over 65 and do not currently use a medical device")

49. When healthcare professionals recommend or provide a home use medical device what factors do you think they consider before making that recommendation? *

Thank You!

Thank you for taking our survey.

Your response is very important to us and £1.00 will be donated to the British Lung foundation on your behalf.

Just to remind you, all information which is collected about you during the course of the research will be kept strictly confidential. If you would like more information or have any questions please contact myself, Ross Thomson, or my supervisor Dr Jennifer Martin at The University of Nottingham.
My email address is eexrt1@nottingham.ac.uk Tel: 0115 84 67256 or you can contact Jennifer.martin@nottingham.ac.uk Tel: 0115 84 67255

Click HERE for further information on The Multidisciplinary Assessment of Technology Centre for Healthcare (MATCH) at The University of Nottingham

Appendix 3 Worked example of z-score calculations for hospital doctors

Scores of selecting behaviour in column over behaviour in row

	The device has been tested by real users	Instructions are sufficient to enable correct use	Users receive training prior to use	The device is cost effective	The device has undergone clinical trials	The device reduces clinic/GP appointments	The device has little impact on the home environment	The outward appearance of the device	The patient is offered a choice between.....
The device has been tested by real users		20	20	19	29	26	9	1	7
Instructions are sufficient to enable correct use	30		28	23	28	21	7	1	8
Users receive training prior to use	30	22		24	30	15	11	3	6
The device is cost effective	31	27	26		33	24	12	2	8
The device has undergone clinical trials	21	22	20	17		20	10	4	8
The device reduces clinic/GP appointments	24	29	35	26	30		12	3	8
The device has little impact on the home environment	41	43	39	38	40	38		3	15
The outward appearance of the device	49	49	47	48	46	47	47		41
The patient is offered a choice between.....	43	42	44	42	42	42	35	9	

The table above shows the raw scores of hospital doctors (n=50) answers to the forced choice section of the questionnaire. Reading down the first column, the table shows, for example that 'tested by real users' was selected as more important than 'instructions and sufficient to enable correct use' by 30 participants. Conversely, 'instructions are sufficient to enable correct use' was selected as more important than 'tested by real users' by 20 participants.

Probability of selecting behaviour in column over behaviour in row

	The device has been tested by real users	Instructions are sufficient to enable correct use	Users receive training prior to use	The device is cost effective	The device has undergone clinical trials	The device reduces clinic/GP appointments	The device has little impact on the home environment	The outward appearance of the device	The patient is offered a choice between.....
The device has been tested by real users	0.50	-	-	-	-	-	-	-	-
Instructions are sufficient to enable correct use	0.60	0.50	-	-	-	-	-	-	-
Users receive training prior to use	0.60	0.44	0.50	-	-	-	-	-	-
The device is cost effective	0.62	0.54	0.52	0.50	-	-	-	-	-
The device has undergone clinical trials	0.42	0.44	0.40	0.34	0.50	-	-	-	-
The device reduces clinic/GP appointments	0.48	0.58	0.70	0.52	0.60	0.50	-	-	-
The device has little impact on the home environment	0.82	0.86	0.78	0.76	0.80	0.76	0.50	-	-
The outward appearance of the device	0.98	0.98	0.94	0.96	0.92	0.94	0.94	0.50	-
The patient is offered a choice between.....	0.86	0.84	0.88	0.84	0.84	0.84	0.70	0.18	0.50

The table above shows the conversion of the raw scores of hospital doctors (n=50) to indicate the proportion of times each alternative was chosen over each other option. Reading down the first column, the table shows, for example that 'tested by real users' was chosen over 'instructions are sufficient to enable correct use' by 60 per cent of the subjects. The probability was calculated by dividing the *actual* number of times 'tested by real users' was chosen by the total number of *possible* times that it could have been chosen. In this instance it was 30 divided by 50 = 0.60. Note that the diagonal entries are assumed equal to 0.50, i.e. 'tested by real users' is selected over 'tested by real users' 50 per cent of the time; also, the top right values are the 'mirror image' of those in the bottom left.

***z*-values of the probabilities of selecting behaviour in column over behaviour in row**

	The device has been tested by real users	Instructions are sufficient to enable correct use	Users receive training prior to use	The device is cost effective	The device has undergone clinical trials	The device reduces clinic/GP appointments	The device has little impact on the home environment	The outward appearance of the device	The patient is offered a choice between.....
The device has been tested by real users	0.00	-	-	-	-	-	-	-	-
Instructions are sufficient to enable correct use	0.25	0.00	-	-	-	-	-	-	-
Users receive training prior to use	0.25	-0.15	0.00	-	-	-	-	-	-
The device is cost effective	0.31	0.10	0.05	0.00	-	-	-	-	-
The device has undergone clinical trials	-0.20	-0.15	-0.25	-0.41	0.00	-	-	-	-
The device reduces clinic/GP appointments	-0.05	0.20	0.52	0.05	0.25	0.00	-	-	-
The device has little impact on the home environment	0.92	1.08	0.77	0.71	0.84	0.71	0.00	-	-
The outward appearance of the device	2.05	2.05	1.55	1.75	1.41	1.55	1.55	0.00	-
The patient is offered a choice between.....	1.08	0.99	1.17	0.99	0.99	0.99	0.52	-0.92	0.00
Total Z	4.6	3.87	3.71	2.63	4.5	2.28	-2.96	-12.85	-5.81
Average Z	**0.51**	**0.43**	**0.41**	**0.29**	**0.50**	**0.25**	**-0.33**	**-1.43**	**-0.65**

The table shows the conversion of the probabilities from the previous table in to *z*-values. The z-scores for each column are then summed and averaged.

Appendix 4 Longitudinal study interview schedules

Interview schedule (1st interview)

1) Could you give me a brief history of you COPD?
2) What treatment are you currently on?
3) How does that fit in with your day? *Prompt: do you take as you have been advised?*
4) How does COPD affect your day to day lives? *Prompt: hobbies, relationships, getting out, housework*
5) How did it feel to be told that you/your partner needed an oxygen concentrator? *Prompt: choice?*
6) Have you had any experience of this type of device? What do you expect?
7) How do think the concentrator will fit into the home? *Prompt: where will it be? Where will it be used? Tubing!*
8) What difference do you think the concentrator will have on your lives? *Prompt: Positives and negatives*
9) Have you told friends/family about the concentrator? What have they said?

Interview schedule (2nd interview)

1) Can you tell me what happened on the day the concentrator was delivered? *Prompt: training, choices about positioning etc.*
2) How did you feel when you first saw it? *Prompt: positive and negative emotions*
3) How do you feel when you see it now?
4) Can you tell me in your own words what happens when you use the concentrator?
5) How does that fit in with your day? *Prompt: do you take as you have been advised?*
6) How do you feel when you are using the concentrator? *prompt: physically, emotionally, mentally*
7) How do you feel when your partner is using the concentrator? *prompt: physically, emotionally, mentally*
8) What difference has the concentrator had on your lives? *Prompt: Positives and negatives*
9) How has the concentrator fitted in to the home? Where is it? Have you needed to make any adjustments to rooms or routines?
10) Have your friends/family seen the concentrator? What have they said?
11) If you had to describe what the dialysis machine means to you, what would you say?

    Prompt: What words come to mind, what images? Do you have a nickname for it?

Interview schedule (3rd Interview)

1) How has the concentrator fitted in to the home? Have you needed to make any adjustments to rooms or routines since our last meeting?

2) How do you feel when you see it now?

3) How do you feel now when you are using the concentrator? *prompt: physically, emotionally, mentally*

4) How do you think that has changed?

5) How do you feel now when your partner is using the concentrator? *prompt: physically, emotionally, mentally*

6) How do you think that has changed?

7) How does using the device fit in with your day? *Prompt: do you take as you have been advised?*

8) What difference has the concentrator had on your lives? *Prompt: Positives and negatives*

9) Have your friends/family seen the concentrator? What have they said?

10) If you had to describe what the dialysis machine means to you now, what would you say?

prompt: What words come to mind, what images? Do you have a nickname for it?

Appendix 5 Illustration of paper based analysis

Appendix 6 Persona created for stakeholder event

Fred and Wilma

Wilma is 67 and in relatively good health

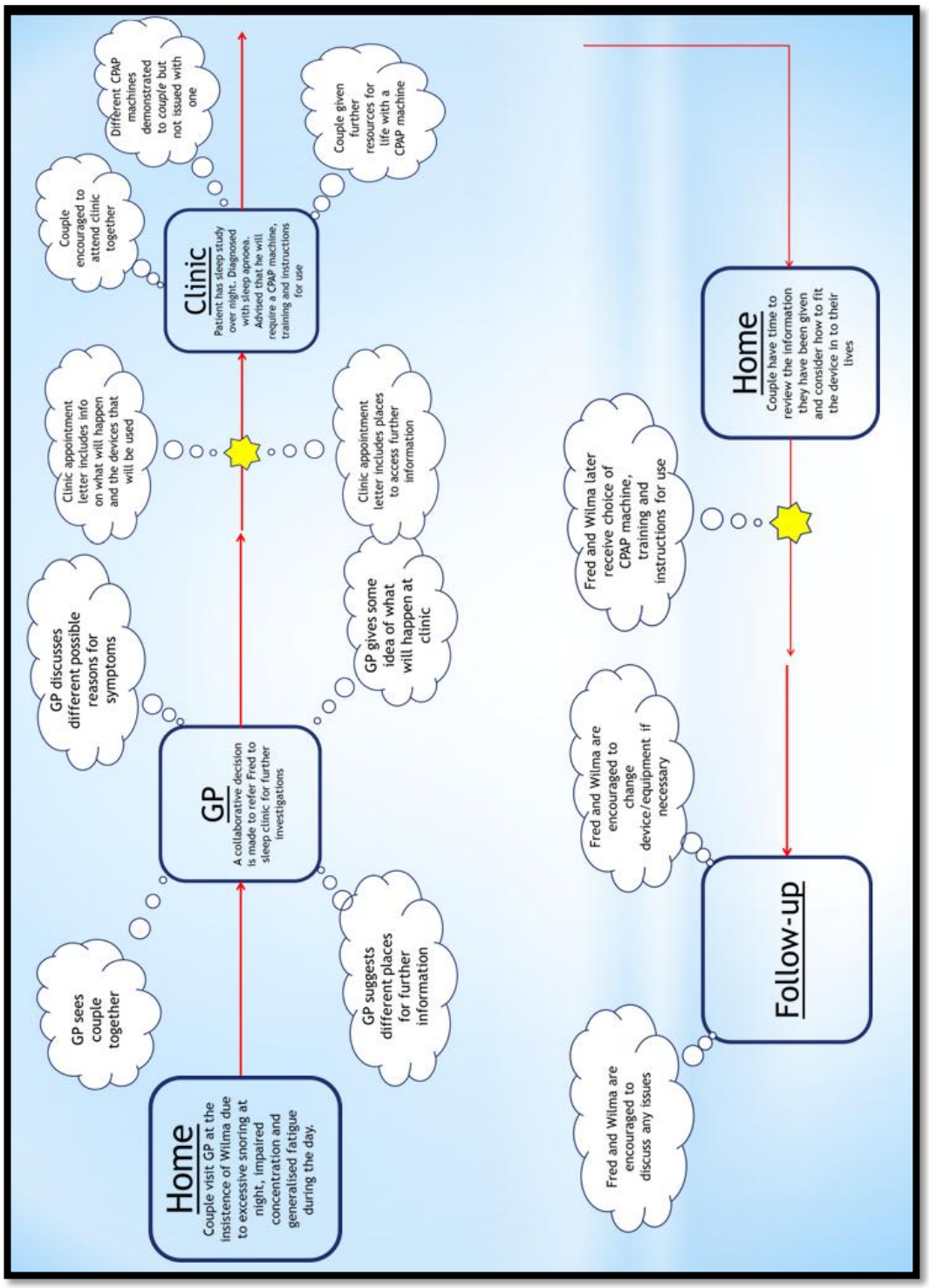
Fred is 68 and has stable COPD managed by his GP

Has been to his GP at the insistence of Wilma due to excessive snoring at night, impaired concentration and generalised fatigue during the day

Referred to sleep clinic at the local hospital

Diagnosed with obstructive sleep apnoea and it is suggested that he be given a continuous positive airway pressure (CPAP) device

Appendix 7 Utopian future scenario presented to participants (interventions based on the findings from the studies included in this thesis are presented in the clouds)



Appendix 8 Examples of stakeholder event data collection